

THE EXPERIENCE OF CAREGIVING FOR PERSONS WITH ADVANCED HEART
FAILURE: AN INTEGRATIVE REVIEW

A Thesis Submitted to the College of Graduate and Postdoctoral Studies

In Partial Fulfillment of the Requirements

For the Degree of Masters of Nursing

In the Department of College of Nursing

University of Saskatchewan

Saskatoon

Submitted By

Alexandra Rae Hodson

PERMISSION TO USE

In presenting this thesis/dissertation in partial fulfillment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this thesis/dissertation in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis/dissertation work or, in their absence, by the Head of the Department or the Dean of the College of Nursing. It is understood that any copying or publication or use of this thesis/dissertation or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis/dissertation.

Requests for permission to copy or to make other uses of materials in this thesis/dissertation in whole or part should be addressed to:

Dean of the College of Nursing
University of Saskatchewan
104 Clinic Place
Saskatoon, Saskatchewan
S7N 2Z4

ABSTRACT

Introduction: It is estimated that the number of people in the advanced stages of heart failure will rise in the future. To meet the high demands of this population, family caregivers will be required to play a large role. Without adequate support, caregivers of persons with advanced HF often have difficulty managing their caregiving role. Access to palliative care services have been shown to reduce caregiver burden; however, referral to these programs is limited. The unique needs of caregivers of persons with advanced HF are not effectively being met and reports of physical and mental health challenges are common.

Objective: The purpose of this review was to outline the state of the literature related to the experience of family caregiving for persons with advanced heart failure and identify gaps that require further research investigation.

Methodology: The method used for this integrative review was based on Whitmore and Knafl's approach to systematically combining quantitative and qualitative literature. A search of CINAHL, Medline, EMBASE and PubMed identified 23 articles that met inclusion criteria. Articles were assessed for quality categorizing each article as either *Strong*, *Moderate* or *Weak*. Data was analyzed using the constant comparison method and coded in NVivo11 (QSR International). Thematic analysis was used to develop themes.

Results: The state of the literature related to caregivers of persons with advanced HF can be divided into six key areas which include: a) undertaking a journey in a state of flux, b) gaining strength, c) forgetting oneself along the way, d) seeking out sources of support, e) preparing for end of life, and f) finding closure.

Significance: There is an incomplete understanding of the experience of caregiving for

persons with advanced heart failure. Specific research gaps included the male perspective, study of participants other than a spouse, Canadian context, positive aspects of caregiving, and caregiver experience during bereavement period.

Conclusion: It is recommended that future research attempt to reduce current gaps in the literature in order to gain a broader understanding of the experience of caregiving for persons with advanced heart failure. This enhanced understanding can then be used as a basis for development of targeted interventions that meet the care needs of this population.

ACKNOWLEDGEMENTS

Thank you to my co-supervisors Dr. Shelley Peacock and Dr. Lorraine Holtslander for your continued motivation and guidance throughout this process. You have both inspired me in my education as well as in my life. Thank you Ms. Maha Kumaran for your assistance with developing my search strategy. Thank you Dr. Andrea Johnson for helping me to realize that I was not happy in my current situation and to work towards following my passion. Thank you Dr. Linda Ferguson for mentoring me throughout my time as a Graduate Teaching Fellow. Thank you Dr. Carol Bullin and Dr. Diane Campbell for agreeing to sit on my committee and for your time and support you have dedicated to my thesis work. Thank you Dr. Vicki Squires for being the external examiner at my defence and offering valuable input that will improve my future work. Thank you to Dr. Jill Bally for being my committee chair, your words of support are frequent reminder to me that “I am not behind, I am right where I need to be.” And finally, thank you to my family. Especially to my husband, Kent Hanson, who is always encouraging me to be the best person I can be. To my son, Odin, who is patient with me when I need to spend a few extra hours on my computer. Odin, your kind nature continually inspires me. I have taken your advice during this process and will “Keep going, even if I make a mistake.” To my Oma, Helen Puttkammer, who has never doubted my ability to complete my Masters and eventually become a Doctor of Nursing.

DEDICATION

This manuscript is dedicated to my dear friend Angela Lindberg (June 22, 1979 – May 6, 2016). You will never know how much you have impacted my life. Your passion for life and positive outlook will continue to inspire me for the remainder of my years.

Table of Contents

PERMISSION TO USE.....	i
ABSTRACT.....	ii
ACKNOWLEDGEMENTS	iv
DEDICATION	v
LIST OF FIGURES	viii
ABBREVIATIONS.....	ix
GLOSSARY OF TERMS.....	x
CHAPTER ONE- INTRODUCTION AND BACKGROUND.....	1
CHAPTER TWO- LITERATURE REVIEW.....	3
2.1 Advanced Heart Failure.....	3
2.2 Caregiver Role	4
2.3 Unmet Needs	4
2.4 Palliative Care in Advanced Heart Failure.....	5
2.5 Challenge of Accessing Palliative Services	6
2.6 Gaps in the Literature.....	7
2.7 Significance of this Research	8
CHAPTER THREE- METHOD	10
3.1 Research Question and Problem Statement.....	10
3.2 Relevance of the Study	10
3.3 Integrative Review Methodology	11
3.3.1. Problem identification	11
3.3.2. Literature search.....	12
3.3.3. Data evaluation.....	14
3.3.4. Data analysis	15
3.3.5. Presentation	16
3.4 Researcher's Role	17
3.5. Ethical Considerations	18
3.6. Findings	18
3.7. Project Committee Members.....	18
CHAPTER FOUR- RESULTS.....	20
4.1 Sample	20
4.2 Undertaking a Journey in a State of Flux	21
4.2.1 Changes in plan of care.....	21
4.2.2. Financial challenges.....	22
4.3 Gaining Strength	22
4.3.1. Developing new skills.....	22
4.3.2. Growing together.....	23
4.4. Forgetting Oneself Along the Way.....	24
4.4.1. Neglect of personal health.....	24
4.4.2. Making sacrifices	25
4.5. Seeking Out Sources of Support	25
4.6. Preparing for End of Life	26
4.6.1. Mental preparedness.....	27

4.6.2. Educational concerns	28
4.6.3. Making difficult decisions.....	28
4.7. Finding Closure	29
4.8 Key Message.....	29
4.9 Summary of Key Themes.....	30
CHAPTER FIVE- DISCUSSION.....	32
5.1 Themes.....	32
5.1.1 Undertaking a journey in a state of flux.....	32
5.1.2 Gaining strength.....	33
5.1.3 Forgetting oneself along the way	34
5.1.4 Seeking out sources of support	35
5.1.5 Preparing for end of life	36
5.1.6 Finding closure.....	38
5.2 Gaps Identified.....	39
5.2.1 Participants.....	39
5.2.2 Canadian context.....	40
5.3 Recommendations for Research.....	41
5.4 Limitations	42
CHAPTER SIX- CONCLUSION.....	45
References.....	47
Appendix A.....	64
Appendix B.....	65
Appendix C.....	66
Appendix D.....	70
Appendix E.....	73

LIST OF FIGURES

Figure 1- Data summary table template.....16

ABBREVIATIONS

HF	Heart Failure
LVAD	Left Ventricular Assist Device
NYHA	New York Heart Association

GLOSSARY OF TERMS

Advanced heart failure- A person who has been diagnosed with heart failure and is considered to be in Stage III or IV of the New York Heart Association Classification or Stage D of the American Heart Association Classification.

American Heart Association Stage D- “Objective evidence of severe cardiovascular disease. Severe limitations. Experiences symptoms even while at rest.” (American Heart Association, 2016)

Bereavement- The emotions experienced following the death of a person that you are personally invested in. This period is often characterized by feelings of grief and can extend from weeks to years in some cases (Buckley, McKinley, Tofler, & Bartrop, 2010).

Caregiver burden- The negative physical and psychological effects that caregivers experience when they struggle to manage the caregiving role (Phillips, Gallagher, Hunt, Der, & Carroll, 2009).

Caregiver strain- The amount of tasks that a person is required to undertake as a result of their role as caregiver (Phillips et al., 2009).

End of life- The point in care delivery where patient’s HF no longer responds to medical treatment and patient is not a candidate for a heart transplant or implantation of a left ventricular assist device (LeMond & Allen, 2011).

Family caregiver- A person who is providing physical and/or emotional care to a family member or friend without financial incentives.

Left Ventricular Assist Device (LVAD)- An electronic device that is surgically implanted inside a patient which assists in moving blood effectively through the heart. The device is controlled by an external power supply (McCarthy et al., 1998).

New York Heart Association Class I- “No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnea” (American Heart Association, 2015).

New York Heart Association Class II- “Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea” (American Heart Association, 2015)

New York Heart Association Class III- “Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea” (American Heart Association, 2015).

New York Heart Association Class IV- “Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases” (American Heart Association, 2015).

Palliative Care- A wholistic, family centered approach to care provision that focuses on enhancing general well-being for persons affected by a life limiting disease (World Health Organization, 2016).

CHAPTER ONE- INTRODUCTION AND BACKGROUND

In 2011, it was estimated that half a million people in Canada were experiencing life with heart failure (HF) (Heart and Stroke Foundation, 2011) and Canadian statistics suggest that this number will continue to rise (Heart and Stroke Foundation, 2015). Recent developments in cardiac care have contributed to this increase with new HF treatments leading to an extension of the advanced stages (Cubbon et al., 2011). Advanced HF is characterized by periods of acute symptom exacerbation (Browne, Macdonald, May, Macleod, & Mair, 2014) requiring assistance in promotion of health and daily symptom management, a role often performed by a family caregiver (Kitko, Hupcey, Pinto, & Palese, 2015). As the Canadian healthcare system shifts client care from the hospital to the community setting (Public Health Agency of Canada, 2013), there will be an increased need for family members to take on the role of caregiver; however, this shift in service delivery will be unsustainable if we do not provide support for people undertaking this important role. For the remainder of this work family caregiver will be referred to as ‘caregiver’.

Currently in the literature, the voice of the caregiver is often overshadowed by a focus on the needs of the patient. Given the important role that caregivers play in the case of advanced HF, research is needed to understand caregivers’ experience. Caregivers of persons living with advanced HF have a challenging role and the literature suggests that the needs of these caregivers are not being met considering the high reports of caregiver burnout and emotional difficulties (Doherty, Fitzsimons, & McIlfatrick, 2016). To develop interventions that effectively meet the needs of caregivers of persons with advanced HF, we need to first gain an enhanced understanding of their specific experience. An integrative review will allow for the identification of all pertinent data related to caregivers of persons with heart failure, an evaluation of the

quality of the data, and an analysis of the data for the purposes of synthesizing and presenting it to the appropriate audiences. An integrative review will provide a comprehensive view of the current state of knowledge related to the experience of caregiving for persons with advanced HF as well as identify potential gaps in understanding. A focus on the advanced period of HF is warranted as prior systematic reviews in this area are limited. Research has also shown that caregivers providing care to persons with HF in the advanced stages are at an increased risk for mental health concerns and may have increased needs in relation to caregivers of persons in the earlier stages of the disease (Hooley, Butler, & Howlett, 2005; Saunders, 2008).

The purpose of this research is to integrate quantitative and qualitative works regarding caregiving of persons with advanced HF. The results from the integrative review will inform current nursing practice related to caregivers of persons with advanced HF in order to address the unmet needs of this population as well as identify gaps in the current literature. The databases of CINAHL, Medline, EMBASE and PubMed were searched using the following MESH terms, keywords and their derivatives: heart failure, caregiver, advanced heart failure, cardiac failure, left sided heart failure, myocardial failure, congestive heart failure, family caregiver, informal caregiver, spouse, neighbour, friend, son and/or daughter. Articles were limited to English only. The aims of this research were to: a) develop a comprehensive view of the literature that currently exists relating to the experience of caregiving for persons with advanced HF and b) identify gaps in this body of research. From this enhanced understanding, health care practitioners will be able to advocate for improved services for caregivers of persons with advanced HF. For purposes of this thesis family caregiver (as noted earlier) will be referred to as ‘caregiver’ and persons with advanced HF will be referred to as ‘patient’ for the remainder of the discussion.

CHAPTER TWO- LITERATURE REVIEW

This chapter will introduce and summarize background literature related to the experience of caregiving for persons with advanced HF. Readers of this chapter will gain a basic understanding of the definition of advanced HF, tasks related to the role of caregiver of persons with advanced HF and common challenges they face. Palliative care is an important topic to address within the context of advanced HF because access to services offered through a palliative approach can improve the caregiver's experience at end of life (Small et al., 2009); as such, chapter two will identify concepts of palliative care as it relates to HF and barriers to access of palliative services. The chapter will conclude with a preliminary understanding of current gaps in the literature related to caregiving for persons with advanced HF.

2.1 Advanced Heart Failure

Advanced HF is commonly defined in the literature as persons who meet criteria 3 or 4 of the New York Heart Association or Stage D as classified by the American College of Cardiology and American Heart Association (American Heart Association, 2012). Symptoms during this period include fatigue, edema, pain, shortness of breath and mental health challenges such as anxiety and depression (Adler, Goldfinger, Kalman, Park, & Meier, 2009). Although it is not always clear as to when a patient enters the advanced stages of HF, key criteria have been identified that indicate a person may be in the advanced period including a noted increase in the frequency of hospitalizations and an inability to relieve symptoms despite appropriate treatments (Glogowska et al., 2016; Hupcey, Kitko, & Alonso, 2016). When a patient enters the advanced period of HF, their needs increase (Browne et al., 2014) and research has shown that an inability to meet these needs can contribute to feelings of caregiver burden (Doherty, McIlfratrick, & Fitzsimons, 2015).

2.2 Caregiver Role

A current trend in chronic disease management is the transition from a primarily hospital-based care model to a community-based approach (Hayes et al., 2015). With this shift in service delivery, caregivers will be required to play a key role in helping to meet the high demands of persons with advanced HF (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006). The role of the caregiver of persons with advanced HF include management of complex medication regimens, monitoring patient daily weights, enforcing dietary requirements such as limiting salt intake, and encouraging patient participation in physical activity (Browne et al., 2014; Kitko & Hupcey, 2013). These tasks are both emotionally difficult and physically intensive creating a situation where caregiver burden is common. The way of life for the caregiver is sometimes described as a constant state of anxiety created by the need to closely monitor the patient for signs and symptoms of HF, even during periods of illness stability (Braannstrom, Ekman, Boman, & Strandberg, 2007; Kitko & Hupcey, 2013).

Symptoms experienced in advanced HF also severely limit the patient's ability to assist with management of the household, creating a high risk for the potential of caregiver burden (Adler et al., 2009; Kitko & Hupcey, 2013). The risk for caregiver burden increases when caregivers are required to attend multiple medical appointments, often receiving conflicting advice on how to effectively care for their loved one or patients are being sent for unnecessary tests (Browne et al., 2014; Kitko & Hupcey, 2013; Wingham et al., 2015).

2.3 Unmet Needs

It is important to support the needs of caregivers as they play a vital role in promoting health and managing symptoms of persons with advanced HF (Hupcey, Fenstermacher, Kitko, & Fogg, 2011). When the needs of the caregiver are not met, they are at

increased risk of detrimental mental and physical health outcomes, creating a situation where they have difficulty fulfilling their vital role (Evangelistaa, Stromberg, & Dionne-Odom, 2016; Timonet Andreu et al., 2015). When a caregiver is unable to perform their role effectively, the literature suggests that hospitalization rates of persons with HF are increased (Aggarwal, Pender, Mosca, & Mochari-Greenberger, 2015). Consensus exists amongst researchers that many of the needs of persons with advanced HF can be effectively addressed by gaining access to palliative care services (Bowers, 2013; Howlett et al., 2010), thus creating a situation where implementation of palliative services could serve to alleviate or reduce feelings of caregiver burden.

2.4 Palliative Care in Advanced Heart Failure

HF is a life limiting disease that will eventually lead to death (Howlett et al., 2010). Following a diagnosis of HF, it is typical for 50% of patients to die within five years (Hupcey et al., 2016). Palliative care services are beneficial as they can help the caregiver and patient, focus on improving quality of life and address issues that may arise as a result of the process of dying (Canadian Hospice Palliative Care Association, 2013). Palliative care services do not cease with death of the patient but instead extend beyond to assist families during the bereavement period (Canadian Nurses Association, 2014). As a patient with advanced HF moves towards the end of life, it is important for families to have access to palliative care services that will encourage them to reflect on life experiences, accept death as a likely outcome, as well as focus energies on enjoying their remaining days (McWilliam, Ward-Griffin, Oudshoorn, & Krestick, 2008).

High quality palliative care at end of life is a basic human right for all Canadians (Parliament of Canada, 2000; Stajduhar, 2011). However, current estimates of utilization show that less than 10% of patients with HF receive appropriate end-of-life services (Gelfman,

Kalman, & Goldstein, 2014; Goodlin, 2009; Ivany, 2015). Cancer continues to be the most common illness for referral to palliative care services despite the diagnosis of cancer accounting for 25% of total deaths in Canada (Parliament of Canada, 2000). The unfortunate reality is that for many families impacted by HF discussions regarding the need to refer to palliative care services are limited (Small et al., 2009). Thus, adequate support is not being provided during this important phase of life. When support is inadequate, patient preferences at end of life are not incorporated into the plan of care leading caregivers to potentially experience remorse about the end-of-life experience (Small et al., 2009).

2.5 Challenge of Accessing Palliative Services

Persons with HF have unique needs that require adaptation of palliative care services to address these challenges (Howlett et al., 2010; Lum et al., 2015). For example, the disease trajectory of HF is unpredictable, characterized by episodes of acute symptom exacerbation, followed by periods of symptom stability (Goodlin, 2009). In comparison to a palliative cancer diagnosis that typically follows a predictable disease progression, a person with HF may either experience a sudden cardiac related death or undergo a slow decline in heart function (Adler et al., 2009; Arnold et al., 2006) making it difficult for health care practitioners to predict when the patient is nearing end of life.

Canadian recommendations suggest health care practitioners working with HF patients should initiate end-of-life discussions early in the disease process (Arnold et al., 2006; Emanuel & Librach, 2011). Literature suggests practitioners tend to feel uncertain about referral to palliative care services as they do not believe they have the appropriate training to initiate end-of-life discussions (Browne et al., 2014; Howlett et al., 2010) and this is unfortunate. Lack of time was also cited in the literature as a common challenge to the involvement in end-of-life

discussions (Browne et al., 2014). Unclear communication about prognosis results in misunderstanding throughout the disease process with the literature citing that caregivers often do not recognize that the patient will eventually die from HF (Gelfman et al., 2014; Goodlin, 2009; Ivany, 2015).

Access to palliative care services is known to increase the likelihood of a peaceful death (Boucher et al., 2010). A peaceful death has been characterized in the HF literature as a period free of pain and unnecessary treatments and a situation where there is effective communication between a limited number of care providers (Boucher et al., 2010; Small et al., 2009). Managing symptoms becomes a priority for end-of-life care as this contributes to an increase in quality of life (Arnold et al., 2006). Although a peaceful death is important for the patient, it is also equally important for the caregiver; a negative perception of the experience at end of life reduces a caregiver's ability to cope and has been attributed to increased levels of depression in the bereavement period (Small et al., 2009).

2.6 Gaps in the Literature

There have been previous meta-syntheses on the topic of caregiving for persons with HF (e.g., Kang, Li, & Nolan, 2011; Molloy, Johnston, & Witham, 2005); although valuable in their findings, these reviews do not specifically address the advanced stages of the illness. One previous review did limit focus to caregivers of persons with advanced HF; however, discussion was limited to needs of the caregiver (Doherty, Fitzsimons, & McIlfatrick, 2016). To the best of my knowledge, this is the first review that has focused on understanding the experience of caregiving for individuals with advanced HF, including the end of life period through to bereavement. This review also differs from prior literature reviews in that its aim is to expand the search criteria to include quantitative research.

Current Canadian guidelines in HF care have identified that incorporating the caregiver into the plan of care is essential (Howlett et al., 2016); however, current guidelines do not include specific interventions. A review of caregiver interventions for persons with a life limiting illness identified 12 interventions that have been shown to be effective in improving the caregiver's ability to manage their caregiving role (Candy, Jones, Drake, Leurent, & King, 2011) with only 11 of these interventions being developed specifically for caregivers of persons with cancer. Due to unique differences between each diagnosis, it is not advisable to generalize results from one disease population to another and expect the same outcomes (Molloy et al., 2005). This integrative review will provide an important first step in the development of clinical recommendations.

2.7 Significance of this Research

The health care system cannot currently meet the care demands of patients with chronic conditions such as advanced HF (Talley & Crews, 2007); as such, informal caregivers are undertaking key roles in the management of symptoms and promotion of the health of persons with advanced HF (Hupcey, Fenstemacher, Kitko & Fogg, 2011). When caregivers are not adequately prepared for their role as caregiver, both patient and caregiver health and well-being is compromised. For example, when caregivers of individuals with advanced disease exhibited symptoms of anxiety upon discharge from hospital, the patient was more likely to be re-admitted (Goldenheim, Oates, Parker, Russell, Winter, & Silliman, 2014). Multiple studies have reported that caregivers of persons with advanced HF experience high rates of anxiety (Bakas et al., 2006; Bekelman et al., 2011; Brännström, Ekman, Boman & Strandberg, 2007; Kitko & Hupcey, 2013; Saunders, 2008; Small et al., 2009); therefore, a deeper understanding of the caregiving experience could assist in identifying the cause of caregiver anxiety and result in the

development of strategies to minimize its effects. This is just one example of how understanding the caregiving experience could improve the health of both the caregiver and the person with advanced HF; however, other examples exist that can be explored further with research related to the experience of caregiving.

CHAPTER THREE- METHOD

3.1 Research Question and Problem Statement

As a result of the review of the current literature, the research question that drives this work is: “*What is the state of the literature regarding the experience of the family caregiver of a person with advanced heart failure?*” At the present time we know that current services are not addressing the unique needs of these caregivers. Understanding the experience of the caregiver is essential if we want to develop effective care interventions and support services; thus, it is proposed that an integrative literature review will begin to address the current gap in knowledge. As such, the purpose of this integrative review is to understand the experience of caring for a family member with advanced HF.

3.2 Relevance of the Study

Results generated from an integrative review provide a wider scope of the identified problem area as well as serve to generate new knowledge on the topic (Torraco, 2005; Whittemore & Knafl, 2005). This kind of new knowledge generated by an integrative review is important as existing services are not meeting the needs of caregivers of persons with advanced HF and current Canadian cardiovascular guidelines do not include evidence-based interventions that demonstrate how to effectively work with this subset of the population. The current study will identify the extent of the knowledge present in the literature regarding caregivers of persons with advanced HF, ascertain gaps that require further exploration, and provide preliminary practice recommendations based on the results. This review will also contribute to improving the current practice when working with caregivers of persons with advanced HF and serve as a basis for development of evidence informed interventions in the future.

3.3 Integrative Review Methodology

Although a systematic review of quantitative data is the gold standard for synthesizing the effectiveness of interventions (Whittemore, Chao, Jang, Minges, & Park, 2014) a preliminary literature review of research using the keywords “caregiver”, “advanced heart failure” and/or “end-of-life” revealed a small number of experimental studies, thus creating the need for a broader approach to knowledge synthesis in the context of caregivers of persons with advanced HF. A rigorous integrative literature review was utilized to synthesize the state of the knowledge related to the experience of caregivers for persons with advanced HF beyond that of intervention studies alone. An integrative literature review involves the process of combining studies in order to synthesize results from both qualitative and quantitative research in order to generate new knowledge (Whittemore & Knafl, 2005). This type of literature review is an appropriate method to use when the topic area involves a small amount of research (Torraco, 2005) as is the case with research in the area of caregivers of persons with advanced HF.

The structure of this study was based on the integrative review methodology framework presented by Whittemore and Knafl (2005). The areas addressed in this framework include: (a) problem identification, (b) literature search, (c) data evaluation, (d) data analysis, and (e) presentation. This framework was developed to specifically address intricacies commonly encountered during the integrative review process such as the need to combine research from multiple study types. For an integrative review to be considered strong enough to guide future practice, each of the five areas must be addressed. Each area will be discussed in the following section.

3.3.1. Problem identification

Clarity of the problem area to be studied is critical to allow for the appropriate data to be

collected and subsequently analyzed (Whittemore & Knafl, 2005). The *problem* identified that drives the present work is that current supports for caregivers of persons with advanced HF are not meeting the unique needs of this population as evidenced by frequent reports of caregiver burnout and mental health challenges (e.g., anxiety or depression). To provide meaningful support to this population, we must first understand their experience.

3.3.2. Literature search

A rigorous approach to a literature review involves the development of clear directions that serve as a guide for the search process (Booth, Papaioannou, & Sutton, 2012). It is important that the search process is transparent to allow for replication (Coughlan, Cronin, & Ryan, 2013). The goal of the search process for this study was to uncover all relevant information to answer the research question (Booth et al., 2012). To accomplish this, assistance was sought from a professional health sciences librarian and a search strategy was developed. The search was conducted in June 2016. Databases for the search included CINAHL, Medline, EMBASE and PubMed. Search terms were combined using BOOLEAN operators AND/OR. The search strategy included the MESH terms “caregiver” AND “heart failure”, both exploded to encompass all subject headings within the term. Key words used were “heart failure” OR “advanced heart failure” OR “cardiac failure” OR “heart decompensation” OR “right sided heart failure” OR “right-sided heart failure” OR “left sided heart failure” OR “left-sided heart failure” OR “myocardial failure” OR “congestive heart failure” AND “caregiv*” OR “family caregiv*” OR “informal caregiv*” OR “spouse” OR “neighbor” OR “friend” OR “carer” OR “daughter” OR “son”. Keywords were limited to searching within titles and abstracts. All results were limited to human studies and English language.

Once the search strategy was run in all four designated search engines, the resulting 2303 references were uploaded to EndNote. Duplicates were removed leaving 1367 articles. Within Endnote, articles were excluded based on title. Two reviewers (i.e., the graduate student and one of her supervisors) went through the first 200 articles (15%). Once both reviewers were confident that agreement levels were high, one reviewer (the graduate student) continued with the remaining titles. Once all obvious irrelevant titles were removed, the remaining 867 articles were uploaded into DistillerSR. DistillerSR is an online tool that allows for efficient coordination of multiple reviewers.

During the Distiller input process, articles were given a numerical code. Within this program, abstracts were screened by two reviewers. Articles that did not meet relevance criteria based on information from the abstract were excluded. The full text of the remaining 190 articles were then screened using a relevance criteria tool (see Appendix A) that had been entered in DistillerSR. Inclusion criteria were indicated as: (a) all family caregivers over the age of 18 including spouse, adult child, friend and/or neighbor; (b) study indicates patient is palliative, end-of-life and/or in the advanced stages of HF, Class III or IV according of the New York Heart Association (NYHA) and/or Stage D as categorized by the American College of Cardiology and American Heart Association; (c) primary research in peer reviewed journal or unpublished peer reviewed research such as dissertations and theses; (d) article is in English; and (f) article differentiates between the results of the caregiver and the care receiver.

In response to the findings during the relevance criteria process, exclusion criteria were adapted to exclude caregivers providing care for persons who are in the process of receiving a heart transplant or left ventricular assist device (LVAD) insertion. It is well recognized in the literature that people with advanced HF have to make choices regarding opting for transplant or

LVAD to improve their health status however once the patient had the device inserted, they would likely no longer meet criteria for advanced heart failure. Byram (2012) reported that greater than 75% of patients who receive an LVAD see health improvements that move them back to NYHA class I or II. Individuals who already had an LVAD in place and were experiencing symptoms characteristic of advanced HF were still included.

Two reviewers (i.e., graduate student and one of the two supervisors) independently assessed each article for relevance against the above stated inclusion criteria. If a discrepancy was indicated, the article was discussed. Consensus was reached in all cases. The most common reasons for exclusion included a focus on patient outcomes or experience, followed by articles that were not considered to be research (i.e., conference abstract or editorial). Other reasons for exclusion included that results for advanced HF were not reported separately from other diagnoses, results from caregivers were not reported separately from patients, caregivers were professional healthcare workers, and/or a focus on caregiver dyad outcomes. The final sample of articles included 16 using qualitative approaches and 7 using quantitative methods.

A successful literature review aims to locate all relevant research pertaining to the problem under study (Conn et al., 2003), therefore the search process included searching the reference lists of relevant articles to identify any missing articles. A Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram was used to illustrate the details of the search process as stated above (see Appendix B).

3.3.3. Data evaluation

Studies that met the inclusion criteria were then assessed for quality by two reviewers independently (i.e., the graduate student and one of the two supervisors). For the proposed research, qualitative and quantitative research was assessed separately using different quality

appraisal tools. To assess the quality of the quantitative studies, the Quality Assessment Tool for Quantitative Studies was used (see Appendix C). This tool has a strong methodological rating and meets standards for both reliability and validity (National Collaborating Center for Methods and Tools, 2008). Following completion of the tool, each quantitative study can be reported as *strong*, *moderate*, or *weak*.

All qualitative studies were appraised using an adapted Critical Appraisal Skills Programme (CASP) (Duggleby et al., 2010; see Appendix D). The CASP is a tool that includes ten questions, two of which are used for initial screening. The content of the remaining eight questions were individually assessed and each given a numerical value with a *strong* study granted 3 points, *moderate* given 2 points and *weak* given 1 point. The scores of the eight questions were totaled. Studies with scores of 8-13 are considered *weak*, 13-18 are considered *moderate* and 19-24 are considered *strong*. Studies were not excluded based on quality; however, rating scores were taken into account when documenting results.

3.3.4. Data analysis

The data analysis phase of this integrative review involved the exploration of the research articles identified in the literature search phase. To strengthen the resulting themes, Whittemore and Knafl (2005) state a data analysis process should be clearly outlined. For this study, the first step of data analysis was conducted using the process outlined by Pinch (1995) which involved (a) extracting data from each article related to caregivers creating a summary of each article based on preset categories (see Figure 1) and (b) analyzing summaries to develop a tentative outline based on common themes. To confirm and expand on these preliminary themes, articles were coded line by line using NVivo11 (QSR International).

The constant comparative method of coding developed by Glaser (1965) was used to

analyze the data in this study. This method involves reviewing pertinent data within the results and assigning meaning to each part of the text through use of codes. When each area of text is coded, it is compared to previous text labeled with this code. The purpose of this method is to begin generating comparisons within and between categories to aid in the development of a theoretical explanation of results. After all lines had been coded, each code was analyzed and grouped according to themes. Titles for themes were created and discussed with co-supervisors and the final draft of the results developed. Please see Chapter 4 for these results.

Figure 1
Data summary table template

Source	Purpose/Problem	Sample	Design	Instrument	Results	Implications	Country of Origin/Comments/ Quality Appraisal Score

3.3.5. Presentation

With this review, all search processes are presented to the reader using the PRISMA (Moher, Liberati, Tetzlaff, & Altman, 2009) (see Appendix B). Results were presented in a research report format with an introduction, methodology, discussion, results and conclusion. A Pinch table was developed in the data analysis phase and includes a summary of each article (see Appendix E). Publication of the integrative review results will be submitted to the peer-reviewed journal *Heart* and a case application article will be sent to the *Journal of Palliative and Hospice Nursing*. Findings will be presented at the *Canadian Cardiovascular Society* annual conference October 2017. A brief report of the results will be developed to present to key members of the Saskatoon Health Region palliative care and heart failure teams. As well, a poster will be developed and presented to the *Canadian Virtual Hospice* for publication on their website. The information contained in this thesis will also be used as a source for mentorship of future grad students through presentation of the research process and

results at University of Saskatchewan Nursing seminars.

3.4 Researcher's Role

For the past seven years, I have worked as a home care registered nurse for the Saskatoon Health Region. Home care is a growing industry with the Canadian Nurses Association (2013) estimating that by 2016, approximately 66% of nursing care will be provided in a community setting. The number of older adults that are able to remain living independently is increasing, with over 90% choosing to live in their own homes (Canadian Institute of Health Information, 2011). As well, working with persons who have chronic conditions such as HF represents a large percentage of the role of the home care nurse (McBride, Beer, Mitzner, & Rogers, 2011). As a result of my involvement with the expanding field of home care, I am well positioned to develop research that will influence nursing practice.

My role as a researcher will also be enhanced due to my connections with key members in the HF community. For example, I am currently a member of a team that is advocating for enhanced palliative care services. This team has been receiving encouragement from management of the Saskatoon Health Region and employees have been allowed paid time to develop a business plan. The goal of this business plan is to demonstrate the feasibility of enhancing palliative care services that are specifically targeted to persons with chronic conditions. I plan to continue seeking opportunities to become involved with groups interested in the needs of caregivers and have been recently asked to participate in meetings relating to caregiving run by the Saskatoon Council of Aging.

As a home care nurse, I have witnessed first-hand the struggles that caregivers of persons with advanced HF experience and how home care nurses have a large role to play in supporting these caregivers. We try to support these caregivers however, with limited time and resources,

the majority of the care we provide is focused on the patient. Caregivers of persons with advanced HF need an advocate and this is the role I aspire to in the future through my research.

3.5. Ethical Considerations

This study meets criteria for ethics exemption as identified in the Tri-Council Policy Statement: article 2.2 (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010); therefore, ethical approval from the University of Saskatchewan Research Ethics Review Board is not required. Criteria for exclusion included the use of information that is accessible by the public such as online articles and publications that can be attained through a library (Canadian Institutes of Health Research et al., 2010). In addition, email contact with a representative from the Research Ethics Board (Beryl Radcliffe, personal communication, July, 13, 2016) identified that an ethics exemption letter was not required therefore an ethics exemption letter was not requested.

3.6. Findings

The findings of this review provide a comprehensive description of the challenges that caregivers of persons with advanced HF experience. The results of this integrative review uncovers gaps that currently exist in the research literature. Identifying these gaps provides direction for future research and serves as a basis to enhance the support provided to caregivers of persons with advanced HF. Please see Chapter 5 and 6 for further discussion related to the findings of the review.

3.7. Project Committee Members

Jill Bally, RN, PhD, Committee Chair

Shelley Peacock, RN, PhD, Co-Supervisor

Lorraine Holtslander, RN, BSCN, MN, PhD, Co-Supervisor

Carol Bullin, RN, BScN, MCEd, PhD, Committee Member

Diane Campbell, RN, PhD, Committee Member

CHAPTER FOUR- RESULTS

The results of this integrative review seek to answer the research question; “*What is the state of the literature regarding the experience of the family caregiver of a person with advanced heart failure?*” This section will include a discussion of general findings and exploration of the resulting themes.

4.1 Sample

Twenty-three research articles met the criteria for inclusion in this integrative review. This included 16 qualitative and 7 quantitative research studies. The date of publications ranged between 2000 and 2016 with countries of publication that included United States (n=14), United Kingdom (n=4), Sweden (n=2), Netherlands (n=1), Canada (n=1), and Australia (n=1). All qualitative research articles utilized semi-structured interviews as their form of data collection. Quantitative research utilized a mixture of researcher developed questionnaires and established instruments to collect data. One potential intervention specific to caregivers of advanced HF was identified and tested and subsequently was deemed to be ineffective with this population. Seventeen of the twenty-three articles focused their purposes solely on the caregiver. The remaining articles included other perspectives from either the patient or a professional caregiver with these results excluded in the data analysis process as they are not the focus of the current review.

The samples size for each study ranged from 3 caregivers of persons with advanced HF to 7324 caregivers with the sample size of all caregivers totaling 7914. The reported age of caregivers ranged from 27 to 94 years. The majority of reported relationships between caregivers and patients were classified as being a spouse (86.3%); the remaining caregiver samples reported a relationship of adult children (10%), sibling (0.9%) parent (0.3%) and other (i.e.

friend) (2.6%). The percentage of people identifying as female within the sample was 74% with the remaining 26% identified as being male. Quality of the articles, assessed using the CASP and the Quality Assessment Tool for Quantitative Studies reported that 5 articles were weak, 11 were moderate, and 7 were strong.

Throughout the data analysis process, six major themes emerged: (a) undertaking a journey in a state of flux; (b) gaining strength; (c) forgetting oneself along the way; (d) seeking out sources of support (e) preparing for the end of life; and (f) finding closure. Each theme will be discussed in the following section.

4.2 Undertaking a Journey in a State of Flux

A state of flux can be defined as living a life of uncertainty, coupled with not knowing what each day will bring. The stories shared by caregivers reflected a sense of uncertainty regarding the future. Although caregivers reported a desire for routine in an attempt to establish a sense of normality (Braannstrom et al., 2007; Brush et al., 2010; Kitko & Hupcey, 2013; Saunders, 2012; Scott, 2001) there was also a recognition that a *normal* state did not exist (Aldred, Gott, & Gariballa, 2005; Kitko & Hupcey, 2013; Luttik, Jaarsma, Veeger & van Veldhuisen; Scott, 2001). Loss of the ability to predict future events resulted in general feelings of discontent (Dracup et al., 2004). The constant state of flux resulted in situations where caregivers declined invitations to events outside of the home allowing them to be isolated from a larger social network (Aldred et al., 2005). The state of flux is further revealed through continuous changes to patient care plans and related financial obligations.

4.2.1 Changes in plan of care. Characteristics of this state of flux included frequent changes to medication regimens, frequent introduction of new treatments, and the ongoing need to relearn care strategies (Hupcey et al., 2011; Scott, 2001); for example, one caregiver reported

relief in knowing that when the patient started wheezing, he was heading towards a health crisis, alerting the caregiver that they should seek professional support (Kitko & Hupcey, 2013). As the patient neared end of life, the patient no longer exhibited these signs, decreasing the caregiver's ability to predict future health needs. Experienced caregivers recognized that to be successful in their role, they needed to develop skills that allowed them to adapt to new situations when they arise (Scott, 2001).

4.2.2. Financial challenges. The second subtheme related to flux is concerned with caregiver finances. Financial challenges can be defined as the inability to meet the financial obligations required to provide food and shelter as well as to maintain health such as to purchase medications. The unpredictable nature of a diagnosis of advanced HF contributed to financial challenges for caregivers (Hupcey, Fenstermacher, Kitko, & Penrod, 2010; Hupcey et al., 2011; Kitko & Hupcey, 2013; Scott, 2000, 2001). This occurred at a time when it was typical for additional costs to be incurred such as travel to and from hospital, accommodation, meals, payment for medical treatments, and new medication costs (Hupcey et al., 2010; Hupcey et al., 2011; Kitko & Hupcey, 2013; Scott, 2001).

4.3 Gaining Strength

The theme of gaining strength encompasses the personal growth that the caregiver attributes to the experience of caregiving. Despite reports of feeling overwhelmed by the caregiving role, several caregivers reported an increased sense of satisfaction due to these additional responsibilities (Scott, 2001). Caregivers credited these positive effects of caregiving to the development of new skills and the strengthening of the relationship between caregiver and patient.

4.3.1. Developing new skills. This subtheme includes the development of both

cognitive and physical skills. As a result of undertaking the caregiving role, caregivers gained skills in providing physical care (Aldred et al., 2005; Braannstrom et al., 2007; Kitko & Hupcey, 2013; Saunders, 2012). These skills included wound care, patient assessment for symptom deterioration, titration of medication doses based on pertinent clinical data, and administering intravenous medications in the home environment (Hupcey et al., 2011; Scott, 2001). These skills were often equated with the *job of* a nurse and although they initially proved to be anxiety provoking, once mastered, these tasks contributed to an increase in caregiver self-esteem (Hupcey et al., 2011; Scott, 2001). Skills gained as caregiver could be transferrable to other areas of life; for example, one caregiver reported using her skills learned as a caregiver to improve her own health status (Buck, Zambroski, Garrison, & McMillan, 2013). Another caregiver reported an increase in her ability to problem solve as a result of the experience of caregiving (Scott, 2001).

Multiple caregivers reported a need to compensate for the patient's inability to assist in household activities and therefore were required to learn new skills such as how to cook or fix the car (Aldred et al., 2005; Hupcey et al., 2010; Hupcey et al., 2011; Kitko & Hupcey, 2013; Saunders, 2012; Scott, 2000). This new learning triggered an increase in the confidence of one's own abilities. Caregivers also reported learning strategies to improve mental health such as taking a step back to appreciate the small joys in life and changing their focus to living in the moment (Scott, 2001).

4.3.2. Growing together. The subtheme of growing together entailed both negative and positive aspects. It is evident in the literature that caregivers commonly reported experiencing a sense of frustration and resentment when interacting with the person with advanced HF, specifically when the patient did not attempt to reciprocate care when they had the ability

(Hupcey et al., 2011) or when conversation between the patient and the caregiver was limited (Mårtensson, Dracup, & Fridlund, 2001). In some cases, caregivers undertook their role due to a sense of obligation to the person with advanced HF rather than a desire to provide care (Scott, 2001). Despite these challenges, positive outcomes resulted from the caregiving experience such as the additional time spent with the patient allowed for the development of a deeper relationship (Braannstrom et al., 2007; Scott, 2001). In addition, the psychological support that caregivers provided allowed both the caregiver and the patient an opportunity where time was spent focusing on the positive aspects of life (Aldred et al., 2005; Braannstrom et al., 2007; Kitko & Hupcey, 2013; Scott, 2000). When faced with the inevitability that end of life for the patient may be nearing, the caregiver began to view each additional day with the patient as a gift (Scott, 2001).

4.4. Forgetting Oneself Along the Way

The experience of caregiving for persons with advanced HF involved an intense focus on the patient, often creating a situation where caregivers neglect their own needs in favour of meeting the needs of the patient (Kaasalainen et al., 2011; Walden et al., 2001). Two subthemes emerged from the data: (a) neglect of personal health and; (b) making sacrifices.

4.4.1. Neglect of personal health. Caregivers of persons with advanced HF experience a higher degree of burden to physical and mental health when compared to caregivers of persons with HF who experience low to moderate symptoms (NYHA class I or II) (Pressler et al., 2013). As additional responsibilities common to end of life were added to the role of the caregiver, it became increasingly difficult for them to address their own personal health needs (Hupcey et al., 2011; Saunders, 2012; Scott, 2000, 2001). The limited emphasis on self-care were

in relation to improper diet, poor sleep habits, and failure to make medical appointments for their own health issues (Braannstrom et al., 2007; Kitko & Hupcey, 2013; Scott, 2001).

Caregivers identified that to maintain mental health it was important to participate in activities unrelated to the patient such as watching television, praying, physical activity, lighting a candle, socializing, participating in a hobby, or babysitting grandchildren (Aldred et al., 2005; Braannstrom et al., 2007; Kaasalainen et al., 2011; Kitko & Hupcey, 2013; Murray, Kendall, Boyd, Worth, & Benton, 2004; Scott, 2001); however, caregivers often neglected to take this advice and would only participate in activities outside of the home when the patient's symptoms had been effectively managed (Hupcey et al., 2011; Kitko & Hupcey, 2013). Further, these activities would frequently center on meeting needs of the patient such as obtaining medications (Braannstrom et al., 2007).

4.4.2. Making sacrifices. The experience of caregiving for persons with advanced HF involved making sacrifices which can be defined as discontinuing something you enjoy to allow for participation in another thing of value. For example, caregivers reported being unable to travel, as this was not recommended for the patient (Aldred et al., 2005; Scott, 2001). This resulted in a large percentage of time being spent in the home setting which contributed to a sense of isolation from their surrounding community (Aldred et al., 2005; McMillan, Small, Haley, Zambroski, & Buck, 2013; Saunders, 2012). Due to the time requirements needed to provide care for a person with advanced HF, many caregivers felt they needed to give up hobbies that they had once enjoyed (Aldred et al., 2005).

4.5. Seeking Out Sources of Support

Within this study, sources of support are defined as any person or service that would assist in reducing the work of the caregiver. The advanced period of HF is hectic and as such,

caregivers are required to seek out additional sources of support. Sources of support identified by caregivers included other family members, friends and professional members of the healthcare team. Although help was necessary, supports were not always available when requested (Aldred et al., 2005; Small et al., 2009). Caregivers admitted to being hesitant in requesting assistance as they felt others were too busy to provide support and/or they did not want to be seen as a burden (Buck et al., 2013; Hupcey et al., 2011; Murray et al., 2004; Scott, 2001). Support from a palliative care team was seen as an asset (Braannstrom et al., 2007; Hupcey et al., 2010; MacKenzie, Buck, Meghani, & Riegel, 2016); however, persons impacted by advanced HF were not consistently referred to these sources of support (Davidson, Abernethy, Newton, Clark, & Currow, 2013; Kaasalainen et al., 2011).

The quality of support the caregiver received during the advanced period through to end of life appeared to have a strong influence on whether the experience of caregiving was seen as positive or negative (Buck et al., 2013; Mårtensson, LeCouteur, & Croom, 2001). Interventions viewed as supportive included arranging for assistance with physical care, encouraging contact for personal needs rather than solely focusing on the patient, and allowing time for discussion about the caregiving experience using positive language (Mårtensson et al., 2001; Murray et al., 2004). Caregivers also felt supported when they were given straightforward information about the patient's needs and current health status (Hupcey et al., 2011; Walden et al., 2001). A negative experience of caregiving was reported when professionals providing support appeared rushed, when outside support did not provide information to the caregiver, or when communication was lacking between supportive services (Aldred et al., 2005; Braannstrom et al., 2007; Kitko & Hupcey, 2013; Mårtensson et al., 2001; McIlvennan et al., 2016; Saunders, 2012).

4.6. Preparing for End of Life

Preparation for end of life includes any task that would assist caregivers in the transition from active treatment to acceptance of the possibility of death of the patient. Caregivers providing care to persons with HF at end of life reported varying degrees of preparedness related to the possibility of death. Areas of preparation reported by caregivers were focused in three main areas: (a) mental preparedness, (b) educational concerns, and (c) making difficult decisions.

4.6.1. Mental preparedness. Lack of or delayed discussion about the topic of end of life created a barrier for caregivers to become mentally prepared for the possibility of death of the patient. Caregivers reported knowing that death in the near future was plausible (Aldred et al., 2005; Murray et al., 2004; Scott, 2001) but, health care providers had not brought the topic up with them and caregivers felt uncomfortable initiating the conversation (Aldred et al., 2005; Braannstrom et al., 2007; Murray et al., 2004; Small et al., 2009). Caregivers reported relief when a health care professional would broach the subject of end of life as it allowed them to begin to develop a plan for the future (Brush et al., 2010). Conversations about death between the caregiver and patient were challenging and tended to be avoided (Braannstrom et al., 2007; Selman et al., 2007; Small et al., 2009). Reasons cited for this avoidance included a wish to maintain a sense of optimism for the patient, feeling uncomfortable about the topic of death and dying and/or a lack of knowledge about how to address the matter (Aldred et al., 2005; Small et al., 2009). Once the patient had died, caregivers reported that they had not been mentally prepared for this experience (Davidson et al., 2013; Hupcey et al., 2010). Caregivers that received support through palliative care or had access to hospice services were more likely to report being mentally prepared for death or the possibility of death in the future (Hupcey et al., 2010).

4.6.2. Educational concerns. If caregivers were able to acknowledge that HF was a life-limiting illness, they attempted to prepare themselves for end of life by gathering knowledge. Educational requests included a description of their role when presented with an emergency situation with the potential to result in death including what to do if at home the patient's heart stops or they are unable to breath (Braannstrom et al., 2007; Mårtensson et al., 2001; McIlvennan et al., 2016; Selman et al., 2007). Caregivers also reported an eagerness to visualize the end-of-life experience, questioning if pain or anxiety for the patient would be involved (Brush et al., 2010; McIlvennan et al., 2016). These questions commonly remained unanswered, creating a sense of frustration and confusion for caregivers (Aldred et al., 2005; McIlvennan et al., 2016; Small et al., 2009). Caregivers who had already experienced a person dying from HF reported multiple end-of-life scenarios including sudden death, gradual worsening of symptoms, or rapid improvement followed by an unexpected death (Brush et al., 2010; Hupcey et al., 2010; Small et al., 2009). As such it is difficult to predict which disease trajectory with which the caregiver will be presented with.

4.6.3. Making difficult decisions. As the persons with advanced HF showed a significant deterioration in health status, caregivers found themselves assisting patient's in making choices that would influence the end-of-life experience. A common decision required of caregivers concerned whether or not to access palliative resources such as home care or hospice (Braannstrom et al., 2007; Hupcey et al., 2011). Other decisions were related to patient hospitalizations such as the decision on whether to bring the patient to the hospital for symptom relief versus staying at home to manage care (Aldred et al., 2005), the decision to decline tests and procedures at end of life that the family deemed unnecessary (Aldred et al., 2005; Small et al., 2009) or the decision to discontinue current life prolonging treatments including medications

and deactivation of a LVAD (Brush et al., 2010; McIlvennan et al., 2016). Caregivers reported that decisions at end of life were based on what would provide the best quality of life for the patient and would result in the lowest degree of pain and anxiety (Selman et al., 2007).

4.7. Finding Closure

The experience of caregiving does not end once the patient dies. The theme of finding closure illustrates the experience of the caregiver during the bereavement period. Findings during this period were conflicted with some caregivers reporting an increase in socialization while others reporting that they remained isolated (Small et al., 2009). All caregivers discussed some level of grief following the death of the person with HF (Davidson et al., 2013; Small et al., 2009) with a high percentage reporting that they were able to eventually overcome their grief (Davidson et al., 2013). Professional support during the bereavement period was seen as beneficial but support services were not commonly accessed by the caregiver (Davidson et al., 2013; Small et al., 2009). Discussion related to the bereavement period was limited to two articles (Davidson et al., 2013; Small et al., 2009) from the twenty-three found in this review, indicating a need for further research development in this area.

4.8 Key Message

The experience of caregiving for persons with advanced HF can be comparable to obtaining employment in a position where you do not have the required qualifications. As one participant explained her thoughts on the caregiving experience “I am not a nurse, I never even wanted to be a nurse” (Scott, 2001, p. 230). Each day as a caregiver brings with it a new learning challenge and just as you begin to feel as if you have mastered the role, an additional skill is added to your list of learning requirements. Learning how to perform your *new job* as caregiver of a person with advanced HF is a process that tests your ability to be flexible while continually

being presented with road blocks. This role as caregiver may not have been the path you imagined but you continue to do it because of a sense obligation and in fact, you may be the only potential candidate for the position. The caregiving experience was described by another participant as a “huge life adjustment” (Hupcey et al., 2010, p. 218). As health care practitioners, we should remind ourselves of the life adjustment that was once required when we first entered school to train for our profession. Learning required hours of reading and continual practice. Skills did not always come easy and with that, sometimes came anxiety and frustration. Caregivers are delving into a new world where they may be struggling to understand the terminology and do not feel they have the confidence nor the skills to perform the amount and type of care that our health care system is asking of them. It is our job to assist caregivers in preparing for their role, making sure to be patient and provide all the needed encouragement along the way.

4.9 Summary of Key Themes

Throughout all twenty-three articles in this review, there was an overwhelming sense of unpredictability that accompanied the experience of caregiving for persons living with advanced HF. Caregivers who were successful in their role had the ability to adapt to frequent care plan changes and be prepared for the unexpected. This lack of normality created a situation where financial challenges were a common concern. Caregivers had difficulty establishing a balance between meeting their own needs and the needs of the patients, but despite frequent struggle, value was placed on the caregiving experience as it allowed them time to build a strong relationship with the patient and resulted in an increased sense of self-worth. As the patient’s health declined, caregivers assisted in making critical decisions that would impact the end of life experience. The focus of these decisions centered around maintaining comfort for the patient.

Discussions surrounding the end-of-life experience were limited and caregivers did not feel adequately prepared for the future possibility of death. When the patient died, the needs of the caregiver continued; however, support services often ceased at this time. A perceived lack of support permeated the entire experience of caregiving for persons with advanced HF. Caregiving for persons with advanced HF impacts all areas of life and caregivers are forever changed by their experience.

CHAPTER FIVE- DISCUSSION

Throughout this section I will address each theme and relate it to previous caregiving research. Completion of this review has also allowed for valuable insights; therefore, knowledge gaps and practice recommendations will be discussed. This section will close with suggestions for future research and study limitations.

5.1 Themes

5.1.1 Undertaking a journey in a state of flux

The caregiving experience represented in this review follows an unpredictable path, lacking in a sense of normalcy. These findings have been reflected in literature describing the illness trajectory of people living with an advanced chronic condition (Bove, Zakrisson, Midtgaard, Lomborg, & Overgaard, 2016) which often involves sudden acute symptom exacerbations followed by periods of stability (Lynn, 2001). In this review, the experience of uncertainty of the future is referred to as a state of flux. Harris, Adams, Zubatsky and White (2011) used the phrase *state of flux* to characterize the emotional connection between caregiver and persons with dementia, where there is a continual need to redefine the relationship as the patient experiences mental decline. A state of flux was also used in the literature to describe the experience of caregivers of grandchildren with autism spectrum disorder (Margetts, Le Couteur and Croom, 2006). This experience was reported to involve a constant desire to balance the preferences of the parents with the needs of the child living with autism.

The uncertainty surrounding the everyday experience of caregiving contributed to a decreased sense of well-being for caregivers (Dracup et al., 2004); as such, it is recommended that healthcare professionals assess the physical and emotional needs of the caregivers at each encounter and intervene when appropriate. The caregivers within this review also indicated the

unpredictable nature of the experience of caregiving was isolating due to refraining from making plans in case the patient became ill. These commonly reported feelings of isolation is an important issue to address as social isolation has been shown to increase the risk of caregiver burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). When caregivers of patients with early stages of dementia were compared to patients in the late stages, the caregivers of persons with advanced dementia reported greater feelings of isolation (Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). Previous reviews related to caregivers of individuals with HF that included both early stage and advanced HF (as noted in Chapter 2) also reported social isolation in their finding (Kang, Li, & Nolan, 2011; Molloy et al., 2005) but, it is possible that the social isolation felt in caregiving for individuals with advanced HF is more pronounced than for caregivers experiencing earlier stages of the disease.

5.1.2 Gaining strength

In previous research, positive aspects of the caregiving experience have been cited including development of a deeper relationship with the care receiver, increase in personal abilities, an enhanced sense of self, and a feeling of personal satisfaction (e.g., Cohen, Colantonio, & Vernich, 2002; Peacock et al., 2010). The current study reflects similar findings where the act of caregiving encouraged the development of new skills and fostered the growth of a strong relationship between caregiver and patient. These results were found in other areas of research; for example, a study by Furlong and Wuest (2008) showed that the experience of caregiving for persons with dementia involved the constant need to gain additional skills. However, this was seen as a negative aspect of caregiving as the caregiver was never able to feel like an expert in their role. The literature suggests that the development of certain skills, particularly skills that if done incorrectly had the potential for adverse events, served to increase

caregiver anxiety (Reimche & Salcedo, 2016) rather than increase caregiver strength. Caregiver anxiety was a key theme in a prior systematic review of caregivers of persons with HF (Kang, Li, & Nolan, 2011); however, the result of that review was not specific to advanced HF, indicating that high levels of anxiety may be a concern throughout the entire HF disease process. It is recommended that the role of the health care professional includes assessing the learning needs of the caregiver and provide ongoing teaching and support throughout the entire caregiving experience.

In this review, relationship growth was limited to discussion on the connection between caregiver and patient. Further exploration into caregiving literature related to autism and mental health expands on this discussion to include strengthening of relationships between in-laws and adult children (Margetts, Le Couteur, & Croom, 2006; Park, 2012). As reported in the current review, caregiving has both a positive and negative effect on the relationship between the caregiver and the patient. This phenomenon is also evident in literature related to caregivers of persons with cancer; however, research in this area appeared to focus on the positive effects of caregiving on the relationship such as opening up communication channels (Jo, Brazil, Lohfeld, & Willison, 2007). Future research could explore the effect of disagreement within the caregiving relationship and its impact on the caregiving experience.

5.1.3 Forgetting oneself along the way

The results of this review highlight the tendency of caregivers to ignore self-care needs and abandon activities that provide personal enjoyment. These findings are supported in other caregiving literature as caregivers frequently report a lack of self-care and a tendency to put the needs of the patient before their own (Gary, 2006; Morgan, Ann Williams, Trussardi, & Gott, 2016); there is an exception with one study where caregivers of persons with dementia reported

an ability to participate in self-care tasks when the condition of the patient was stable (Furlong & Wuest, 2008). It is unclear whether this is the case for caregivers of individuals with advanced HF, as caregivers of individuals with HF feel that their role does not lessen when a patient is stable, but rather the nature of the role changes (Kitko & Hupcey, 2013).

Caregivers who have successfully learned how to balance the needs of the patient with their own personal needs reported having a greater ability to manage the daily challenges they face (Furlong & Wuest, 2008) but the higher the stress of the caregiving situation, the less likely the caregiver will be able to implement health promoting behaviours (Furlong & Wuest, 2008). The above reflects the complexities of the topic of self-care as an issue that involves multiple contributing factors. Psycho-social factors also effect self-care practices. For example, caregivers who believe they deserve self-care are more likely to seek out activities that satisfy this need (Lu & Wykle, 2007); therefore, it may be difficult to detach the effects of personality on self-care versus the effects of the caregiving experience. The topic of self-care in caregivers of persons with HF requires further exploration. To promote caregiver self-care it is recommended that health care professionals encourage caregivers to access respite services to allow them time to meet their own individual needs. Promoting the participating of activities outside of the home during this respite time could contribute to reduced feelings of isolation. Health care professionals could assist caregiver's in identifying these activities if necessary.

5.1.4 Seeking out sources of support

This review presented the experience of caregiving for individuals with advanced HF as involving the coordination of support services (both formal and informal) to ensure that the patient's needs are met. The quality of this support network was shown to have an important impact on the experience of caregiving. A study that included caregivers of patients with

advanced cancer patients showed similar results in that dysfunctional communication within the healthcare team resulted in a negative caregiving experience (Harris et al., 2011).

Barriers in the accessibility of palliative services was also identified in this review as an issue for caregivers of persons with advanced HF. Patients with chronic obstructive pulmonary disease (COPD), a disease with a comparable disease trajectory to HF, encountered limitations with accessing palliative services (Curtis, 2008). Reasons cited for this included a lack of adequate communication about the life limiting nature of the diagnosis and an inability to predict when end of life will occur, which are identical to the challenges that caregivers of individuals with advanced HF experience. It may be beneficial for key players from both COPD and HF to work together to develop a strategy to improve patient services at end of life. In general, there are a multitude of reasons that a caregiver may not have adequate access to support services which are unique to the caregiver (Adelman et al., 2014); therefore, interventions to increase access to support services need to be individualized to the specific caregiver.

5.1.5 Preparing for end of life

Within this review, caregivers who had experienced the death of the patient commonly expressed that the event had not been anticipated and were therefore not prepared for end of life (Hupcey et al., 2010; McIlvennan et al., 2016; Small et al., 2009). Reasons cited for this were lack of education about what to expect at end of life and noted improvements in health just prior to death. An unexpected death has been shown to increase the caregivers risk for ineffective coping during bereavement (Shah et al., 2013). Increased referrals to palliative or hospice services for patients living with advanced HF, preferably at the beginning of the disease trajectory, could assist in preparing families for the end-of-life period (Howlett et al., 2010) increasing the likelihood that caregivers will effectively cope with feelings of grief in

bereavement. Emotional distress that results from ineffective coping during bereavement can increase the caregiver's risk of mortality (Stroebe, Schut, & Stroebe, 2007). Although it is not feasible to provide bereavement services to every person who has taken on the role of caregiver for persons with advanced HF who have died, by investigating what aspects of the experience place people at an increased risk for prolonged grief and ineffective coping, we can target our services to these groups and offer additional supports when necessary (Ghesquiere, Haidar, & Shear, 2011).

Caregivers within this study were involved in key decisions at end of life such as whether or not to deactivate the patient's LVAD. These decisions were made in conjunction with input from the patient. Caregivers of individuals with advanced cancer also reported a joint decision making process with cancer patients in the advanced stages of their disease (Jo et al., 2007) whereas caregivers of persons with dementia reported that due to declining mental health status, it was difficult for patients with advanced dementia to participate in the decision making process (Harris et al., 2011). To feel confident in their decision making ability during the end-of-life phase, caregivers in this study felt they required training related to end of life, specifically on what to do if the patient experiences a health crisis in the home environment. A gap in meeting the informational needs of caregivers who will experience death of their relative has been noted in prior literature (McGuire, Grant & Park, 2012).

Caregivers have a desire for open and honest discussions about death (Thorne, Con, McGuinness, McPherson & Harris, 2004); therefore, it is imperative that health care professionals build relationships with caregivers that allow for these conversations to occur. A therapeutic relationship between caregiver and health care professional would also provide a forum for caregivers to discuss learning gaps such as ones identified in this review, including:

awareness of the life-limiting nature of HF (Aldred et al., 2005; Hupcey et al., 2010) and emergency preparedness in the home environment (Braannstrom et al., 2007; Mårtensson et al., 2001; McIlvennan et al., 2016; Selman et al., 2007). To allow for the healthcare professional to adequately address end-of-life concerns, it is important that they feel comfortable discussing the possibilities of death and therefore, if necessary, they should receive further education and training in the area of palliative care for persons with chronic conditions. It is also recommended that caregivers are aware that HF is a life-limiting disease and that they receive information on possible end-of-life scenarios.

5.1.6 Finding closure

Within this review, only two articles (Davidson et al., 2013; Small et al., 2009) focused on the caregiving experience following the death of the person with advanced HF. It is not uncommon for this phase of the caregiving journey to be neglected in the literature (Ume & Evans, 2011). In clinical practice, nurses providing palliative care state busy schedules do not allow for adequate time to provide support to caregivers in the bereavement period (Johnson, 2015). Not all bereaved caregivers will require support to assist in processing their grief (Faull & Taplin, 2012), and therefore to allow for effective use of resources, services should be prioritized based on need, paying particular attention to caregivers of persons with advanced HF who have unexpectedly died from sudden cardiac death.

Based on the current understanding of the experience of caregiving for persons with advanced HF, it could be argued that this group of caregivers are at an increased risk for complicated grief and failure to cope post death. One reason for this increased risk is related to the frequent reports from caregivers of the lack of effective communication between health care professionals and patients at end of life (Aldred et al., 2005; Braannstrom et al., 2007;

Hupcey et al., 2011; Kaasalainen et al., 2011; Kitko & Hupcey, 2013; McIlvennan et al., 2016). Research has shown that ineffective communication with health care professionals prior to the death of the patient limits the caregiver's ability to effectively manage feelings of loss in bereavement (DiGiacomo, Lewis, Nolan, Phillips, & Davidson, 2013). Discussion regarding the caregiving experience after death within this review identify challenges such as difficulty in processing feelings of grief and lack of interest in participating in activities outside of the home (Davidson et al., 2013; Small et al., 2009). These results highlight the need for future research with the purpose of understanding the experience of bereavement in caregivers of persons with advanced HF. Caregiver support during the bereavement period could be improved through consistent professional follow-up after the person with advanced HF has died.

5.2 Gaps Identified

5.2.1 Participants

The majority of caregiver participants (86.3%) indicated they were a spouse of the person with advanced HF. The large percentage of spouses within the sample limits the generalizability of the current state of the advanced HF caregiver literature as research has demonstrated that spouses report unique caregiving experiences (Penning & Wu, 2016). When compared to adult children (Pinquart & Sorensen, 2011), siblings, parents, and friends (Penning & Wu, 2016), spouse caregivers report a lower quality of life, increased incidence of depression and/or financial strain. Therefore, these measures may be overestimated in the results of this review. Same sex couples have also been shown to have individualized needs based on their distinct experiences such as a perceived feeling of discrimination within the healthcare setting; (Czaja et al., 2016) however, only one same sex couple was included in the studies analyzed for this review. In other bodies of caregiver literature, such as research related to caregivers of

persons with dementia, an effort has been made to analyze each caregiver relationship in isolation (Day, Anderson, & Davis, 2014; Lee et al., 2016; Tan & Schneider, 2009). This approach to research development should be replicated in future research related to caregivers of persons with HF as each relationship offers a unique insight into the caregiving experience.

The male perspective is limited within the literature in this review with males constituting 26% of the caregiver sample. The caregiving experience varies between the male and female population (Hammond-Collins, Peacock, & Forbes, 2014). Cultural background has been shown to influence the experience of caregiving. Cho, Ory, and Stevens (2016) found that when compared to Hispanic and African American caregivers, Caucasian caregivers reported fewer positive aspects of caregiving. The majority of caregivers within this review were Caucasian which could have influenced the reported experiences.

5.2.2 Canadian context

The Canadian context was limited within the literature with only one research article examining a Canadian population. It is likely that the experience of Canadian caregivers would report slightly different experiences that require exploration because where a person resides has a large impact on their experience within the health care system (Hankvisky & Cormier, 2009). One example of this phenomenon was found in a study by Cullen (2007) who analyzed health outcomes of patients within the American and Canadian healthcare systems. The results of this study showed that there was a variance in the number of days that patients were required to spend in acute care following a traumatic brain injury when compared by level of injury. The challenges to health care service delivery due to the large geographical region within Canada also requires further exploration in the context of advanced HF. Research has shown that caregivers living in rural and remote areas within Canada have unique caregiving experiences in

comparison to caregivers living in an urban setting. For example, rural caregivers report barriers in accessing sources of support (Branger, Burton, O'Connell, Stewart, & Morgan, 2016; Brazil, Kaasalainen, Williams, & Rodriguez, 2013).

The sub-theme of financial challenges is another area where differences may be noted when the experience of caregiving is framed within a Canadian context. Caregivers of persons with HF included in this review determined medical care costs to be a common area of concern (Kitko & Hupcey, 2013; Scott, 2000) with reports of refusal to present to the hospital when care was required because they could not afford the medical bill (Hupcey et al., 2011). Due to the publicly funded healthcare in Canada, it is possible that the emphasis placed on financial challenges may either be diminished or shifted to discussions focused on additional costs not covered by government such as visitor parking, home care services, and medications or supplements (Longo, Deber, Fitch, Williams, & D'Souza, 2007).

5.3 Recommendations for Research

The results of this review make evident that when a person takes on the role of caregiver for a person with advanced HF they will be required to spend a large percentage of their time and energy focused on the needs of the patient. Without caregivers, the additional costs to our health care system would be unsustainable (Arno, Levine, & Memmott, 1999; Hollander, Liu, Guining & Chappell, 2009) and therefore it is important that caregivers receive professional support in managing their role. In reality, it appears that much of the professional focus goes to the patient while the caregiver struggles with few resources. Viewing the caregiver in isolation from the patient is impractical as people are highly influenced by the context of their environment (Wright & Leahey, 2005). According to family systems theory, the caregiver and the patient influence the health and wellness of each other (Wright & Leahey, 2005). For example, Kitko and Hupcey

(2013) found that the mental health of the caregiver had a direct impact on the mental health of the patient. In the interest of both the patient and the caregiver, we cannot continue to neglect the needs of caregivers of persons with advanced HF.

From a research perspective, the current understanding of the caregiving experience for persons with advanced HF needs to be expanded. An enhanced understand could be achieved by addressing current gaps in the literature that have been identified within this review. As above, this can include: conducting research within Canada, utilizing participants from different cultural groups, comparing experience by gender, and exploring different relationship structures (such as same sex marriages). Future research should also avoid solely focusing on the negative aspects of the caregiving experience. Representations of a broad and holistic understanding of the caregiving experience in the literature supports the development of effective caregiver interventions (Kramer, 1997).

Finding interventions that support the needs of caregivers of persons with advanced HF should be a priority. Within this review, only one intervention was tested with caregivers of persons with advanced HF and this intervention was shown to be ineffective (Buck et al., 2013; McMillen et al., 2013). The included intervention was entitled *Creativity, Optimism, Planning and Expert Opinion* (known as the COPE intervention) which involved professional guided support through a series of problem-based scenarios commonly encountered when providing care to a person with advanced HF (McMillan, 2013). Perhaps researchers could begin by analyzing the literature to determine what caregiver interventions have been successful in other population groups and test them with caregivers of persons with advanced HF.

5.4 Limitations

As with all studies, limitations existed, one being the exclusion of articles in languages

other than English. The most frequently reported location for participant recruitment was HF clinics, which may have also posed a limitation. In a study by Cassidy (2013), it was found that caregivers recruited from HF clinics reported lower levels of caregiver burden than participants who had been recruited using an online method; therefore, burden levels within the present review may be underestimated. Future research could recruit participants from multiple settings such as online or within the community to offer different perspectives.

Interviews were the primary method of data collection for the articles within this review. Interviews are typically the most commonly used qualitative method in many bodies of research (Hollway & Jefferson, 2013); however, using a variety of methods to gather data for the same study can offer unique interpretation on the topic under investigation (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). For example, a qualitative study that incorporates an observational component could limit bias that may result when studies rely solely on verbal reports from caregivers. Funk and Stajduhar (2009) recommended utilizing observational methods as an addition to interviews. Observation allows researchers to compensate for participants that may be adapting their language within the interview to comply with social norms. Further, interviews included within this review were often conducted jointly between caregiver and patient which made it difficult to separate thoughts of the caregiver from the patient. Patients and caregivers have been shown to report very different levels of satisfaction with experiences in health care (Giovannetti et al., 2013). Although every attempt was made within this review to separate these two experiences when they were combined within one article, it is possible that being present in the same room as the patient created a situation where caregivers filtered or altered their language so as to not upset the patient.

In this discussion, parallels were noted between the current integrative review and

research findings from other populations such as caregivers of individuals with dementia, cancer, COPD, and mental illness, as well as grandparents of children living with autism. Compared to many of the aforementioned populations, research on caregiving of persons with advanced HF appears to still be in its infancy. Future research should focus on addressing current gaps in knowledge that include participants other than the spouse, the bereavement period and the Canadian caregiver experience. Based on the results of this review, recommendations for practice have been presented as a strategy to improve the experience of caregiving for persons with advanced HF.

CHAPTER SIX- CONCLUSION

The intent of this integrative review was to create a thematic framework for the current state of literature related to informal caregiving of persons with advanced HF from the perspective of the caregiver. To our knowledge, this is the first integrative review that sought to bring together all available quantitative and qualitative research specific to the advanced period of caregiving, including end of life and bereavement, for caregivers of persons with HF. Prior to this review, it was noted that as the patient with HF entered the advanced stages of their disease, caregivers were likely to report high levels of physical and emotional challenges with unique needs that were not being met by current services such as palliative care; however, current guidelines provide little direction on how to reduce caregiver burden. To ensure that we are able to effectively meet the needs of the caregiver, we need to first understand the experience of caregiving for persons with advanced HF from the point of view of the caregiver.

The results of this review found that the experience of caregiving for persons with advanced HF is a journey in a state of flux, characterized by the need to adapt each day in response to the inconsistent health status of the patient. Hospitalizations were common during the advanced stages of HF which resulted in challenges such as the inability to meet financial obligations. Caregivers often found themselves absorbed in the constant needs of the patient, while forgetting to meet their own needs. Outside support available to the caregiver to assist them in meeting their needs was limited and when available, tended not to be accessed. Not all reports of caregiving were negative with some caregivers reporting that their journey allowed them the opportunity to learn new skills and to develop a deeper relationship with the patient. Caregivers also expressed concerns about end of life and required assistance to prepare for death and bereavement. The results of this review reflect similar findings in caregiving

literature related to caregiving for persons with dementia, autism, advanced cancer, and/or COPD. Progress in the above mentioned research areas appears to have surpassed the current understanding of caregivers of persons with advanced HF with research demonstrating the impact of caregiving on relationships other than the spouse.

The picture of caregiving for persons with advanced HF remains incomplete with multiple gaps identified in the literature. Priorities for future research include exploring the experience of bereavement and the development of effective caregiver interventions. Future researchers should attempt to recruit a variety of participants into caregiving samples and refrain from overemphasizing the negative aspects of caregiving. Although it will take time to develop a stronger research base, health care professionals working in direct contact with patients with advanced HF can improve the experience of caregiving immediately by implementing small, simple changes into their practice. Improving the experience may be as simple as taking the time to talk to the caregiver, asking for their feedback and ensuring that the caregiver is involved in the care planning process. Caregivers play an invaluable role in the care of persons with HF and they should be seen as a key member of the health care team.

References

- Adelman, R., Tmanova, L., Delgado, D., Dion, & Lachs, M. (2014). Caregiver burden: A clinical review. *Journal of the American Medical Association*, 311(1), 1052.
- Adler, E., Goldfinger, J., Kalman, J., Park, M., & Meier, D. (2009). Palliative care in the treatment of advanced heart failure. *Journal of American Heart Association*, 120, 2597-2696. doi:10.1161/CIRCULATIONAHA.109.869123
- Aggarwal, B., Pender, A., Mosca, L., & Mochari-Greenberger, H. (2015). Factors associated with medication adherence among heart failure patients and their caregivers. *Journal of Nursing Education Practice*, 5(3), 22-27. doi:10.5430/jnep.v5n3p22
- *Aldred, H., Gott, M., & Gariballa, S. (2005). Advanced heart failure: impact on older patients and informal carers. *Journal of Advanced Nursing*, 49(2), 116-124.
- American Heart Association. (2012). Decision making in advanced heart failure: A scientific statement from the American Heart Association. *Circulation*, 125(15), 1928-1952. doi:10.1161/CIR.0b013e31824f2173
- American Heart Association. (2015). *Classes of heart failure*. Retrieved from http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure_UCM_306328_Article.jsp - .WFFnGWU45uY
- American Heart Association. (2016). *Understanding heart failure*. Retrieved from http://www.heart.org/HEARTORG/Conditions/HeartFailure/AboutHeartFailure/Classes-of-Heart-Failure_UCM_306328_Article.jsp - .WCdvr2U45uY
- Arno, P., Levine, C., & Memmott, M. (1999). The economic value of informal caregiving. *Health Affairs*, 18(2), 182.

- Arnold, J. M. O., Liu, P., Demers, C., Dorian, P., Giannetti, N., Haddad, H., . . . White, M. (2006). Canadian Cardiovascular Society consensus conference recommendations on heart failure 2006: Diagnosis and management. *Canadian Journal of Cardiology*, 22(1), 23-45. doi:10.1016/s0828-282x(06)70237-9
- Bakas, T., Pressler, S. J., Johnson, E. A., Nauser, J. A., & Shaneyfelt, T. (2006). Family caregiving in heart failure. *Nursing Research*, 55(3), 180-188.
- Bekelman, D., B., Nowels, C., T., Retrum, J., H., Allen, L., A., Shakar, S., Hutt, E., . . . Kutner, J., S. (2011). Giving voice to patients' and family caregivers' needs in chronic heart failure: Implications for palliative care programs. *Journal of Palliative Medicine*, 14(12), 1317-1324. doi:10.1089/jpm.2011.0179
- Booth, A., Papaioannou, D., & Sutton, A. (2012). *Systematic approach to a successful literature review*. Los Angeles, CA: Sage.
- Bove, D., Zakrisson, A., Midtgaard, J., Lomborg, K. & Overgaard, D. (2016). Undefined and unpredictable responsibility: a focus group study of the experiences of informal caregiver spouses of patients with severe COPD. *Clinical Journal of Nursing*, 25(3-4), 483. doi: 10.1111/jocn.13076
- Bowers, M. T. (2013). Managing patients with heart failure. *The Journal for Nurse Practitioners*, 9(10), 634-642.
- *Braannstrom, M., Ekman, I., Boman, K., & Strandberg, G. (2007). Being a close relative of a person with severe, chronic heart failure in palliative advanced home care: A comfort but also a strain. *Scandinavian Journal of Caring Science*, 21, 338-334.
- Branger, C., Burton, R., O'Connell, M., Stewart, N., & Morgan, D. (2016). Coping with cognitive impairment and dementia: Rural caregivers' perspectives. *Dementia*, 15(4) 814–

831. doi: 10.1177/1471301214539956 dem.sagepub.com

Brazil, K., Kaasalainen, S., Williams, A., & Rodriguez, C. (2013). Comparing the experiences of rural and urban family caregivers of the terminally ill. *Rural Remote Health*, 13(1), 2250.

Browne, S., Macdonald, S., May, C. R., Macleod, U., & Mair, F. S. (2014). Patient, carer and professional perspectives on barriers and facilitators to quality care in advanced heart failure. *PLOS One*, 9(3), 1-8.

*Brush, S., Budge, D., Alharethi, R., McCormick, A., MacPherson, J., Reid, B., . . . Kfoury, A. (2010). End-of-life decision making and implementation in recipients of a destination left ventricular assist device. *The Journal of Heart and Lung Transplantation*, 29(12), 1337-1341.

*Buck, H., Zambroski, C., Garrison, C., & McMillan, S. (2013). Everything they were discussing, we were already doing: Hospice heart failure caregivers reflect on a palliative caregiving intervention. *Journal of Hospice & Palliative Nurses*, 15(4), 218-224.

Buckley, T., McKinley, S., Tofler, G., & Bartrop, R. (2010). Cardiovascular risk in early bereavement: a literature review and proposed mechanisms. *International Journal of Nursing Studies*, 47(2), 229-238. doi:10.1016/j.ijnurstu.2009.06.010

Byram, E. (2012). Upstream palliative care for the patient with a left ventricular assist device as destination therapy. *Dimensions of Critical Care Nursing*, 31(1), 18-24. doi:10.1097/DCC.0b013e31823a537c.

Canadian Hospice Palliative Care Association. (2013). *A model to guide hospice palliative care: Based on the national principles and norms of practice*. Retrieved from <http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf>

- Canadian Institute of Health Information. (2011). *Health care in Canada, 2011: A focus on seniors and aging*. Retrieved from secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada. (2010). *Tri-Council policy statement: Ethical conduct for research involving humans*. Retrieved from http://www.pre.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf
- Canadian Nurses Association. (2013). *Optimizing the role of nursing in home health*. Retrieved from <http://www.cna-aiic.ca>
- Canadian Nurses Association. (2014). *The palliative approach to care and the role of the nurse*. Retrieved from https://www.cna-aiic.ca/~media/cna/page-content/pdf-en/the-palliative-approach-to-care-and-the-role-of-the-nurse_e.pdf?la=en
- Candy, B., Jones, L., Drake, R., Leurent, B., & King, M. (2011). Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database Systematic Reviews*, 6.
- Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. (2014). The use of triangulation in qualitative research. *Oncology Nursing Forum*, 41(5), 545-547.
- Cassidy, T. (2013). Benefit finding through caring: the cancer caregiver experience. *Psychology & Health*, 28(3), 250-266. doi:10.1080/08870446.2012.717623
- Cho, J., Ory, M. G., & Stevens, A. B. (2016). Socioecological factors and positive aspects of caregiving: findings from the REACH II intervention. *Aging Mental Health*, 20(11), 1190-1201. doi:10.1080/13607863.2015.1068739

- Cohen, C., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, 17(2), 184-188.
- Conn, V. S., Isaramalai, S., Rath, S., Jantarakupt, P., Wadhawan, R., & Dash, Y. (2003). Beyond MEDLINE for literature searches. *Journal of Nursing Scholarship*, 35, 177-182.
- Coughlan, M., Cronin, P., & Ryan, F. (2013). *Doing a literature review in nursing, health and social care*. Los Angeles, CA: Sage.
- Cubbon, R. M., Gale, C. P., Kearney, L. C., Schechter, C. B., Brooksby, W. P., Nolan, J., . . . Kearney, M. T. (2011). Changing characteristics and mode of death associated with chronic heart failure caused by left ventricular systolic dysfunction: a study across therapeutic eras. *Circulation Heart Failure*, 4(4), 396-403.
doi:10.1161/CIRCHEARTFAILURE.110.959882
- Cullen, N. (2007). Canadian healthcare perspective in traumatic brain injury rehabilitation. *Journal of Head Trauma Rehabilitation*, 22(4), 214-220.
- Curtis, J. (2008). Palliative and end-of-life care for patients with severe COPD. *European Respiratory Journal*, 32(3), 796–803. doi:10.1183/09031936.00126107
- Czaja, S. J., Sabbag, S., Lee, C. C., Schulz, R., Lang, S., Vlahovic, T., . . . Thurston, C. (2016). Concerns about aging and caregiving among middle-aged and older lesbian and gay adults. *Aging & Mental Health*, 20(11), 1107-1118. doi:10.1080/13607863.2015.1072795
- *Davidson, P. M., Abernethy, A. P., Newton, P. J., Clark, K., & Currow, D. C. (2013). The caregiving perspective in heart failure: a population based study. *BMC Health Services Research*, 13, 342.

- Day, J. R., Anderson, R. A., & Davis, L. L. (2014). Compassion fatigue in adult daughter caregivers of a parent with dementia. *Issues in Mental Health Nursing*, 35(10), 796-804. doi:10.3109/01612840.2014.917133
- DiGiacomo, M., Lewis, J., Nolan, M. T., Phillips, J., & Davidson, P. M. (2013). Transitioning from caregiving to widowhood. *Journal of Pain and Symptom Management*, 46(6), 817-825. doi:10.1016/j.jpainsymman.2013.01.005
- Doherty, L., Fitzsimons, D., & McIlfatrick, S. (2016). Carers' needs in advanced heart failure: A systematic narrative review. *European Journal of Cardiovascular Nursing*, 15(4), 203-212. doi:10.1177/1474515115585237
- Doherty, L., McIlfatrick, S., & Fitzsimons, D. (2015). Earlier integration of palliative care support is needed in advanced heart failure to support caregivers. *European Journal of Cardiovascular Nursing*, 14, 24.
- *Dracup, K., Evangelista, L., Doering, L., Tullman, D., Moser, D., & Hamilton, M. (2004). Emotional well-being in spouses of patient with advanced heart failure. *Heart and Lung*, 33(6), 354-361.
- Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research*, 20(2), 148-158.
- Emanuel, L., & Librach, L. (2011). *Palliative care core skills and clinical competencies* (2nd ed.). St. Louis, MO: Elsevier.
- Evangelistaa, L. S., Stromberg, A., & Dionne-Odom, J. N. (2016). An integrated review of interventions to improve psychological outcomes in caregivers of patients with heart failure. *Current Opinion Support Palliative Care* 10(1), 25-31.

- Faull, C., & Taplin, S. (2012). Adapting to death, dying, and bereavement. In C. Faull, S. de Caestecker, A. Nicholson, & F. Black (Eds.), *Handbook of palliative care* (3rd ed., pp. 81-92). Hoboken, NJ: John Wiley & Sons Inc.
- Funk, L., & Stajduhar, K. (2009). Interviewing family caregivers: Implications of the caregiving context for the research interview. *Qualitative Health Research*, 19(6), 859-867.
- Furlong, K., & Wuest, J. (2008). Self-Care behaviors of spouses caring for significant others with Alzheimer's Disease: The emergence of self-care worthiness as a salient condition. *Qualitative Health Research*, 18(12), 1662-1672. doi: 10.1177/1049732308327158
- Gary, R. (2006). Self-care practices in women with diastolic heart failure. *Heart Lung*, 35(9), 19.
- Gelfman, L. P., Kalman, J., & Goldstein, N. E. (2014). Engaging heart failure clinicians to increase palliative care referrals: overcoming barriers, improving techniques. *Journal of Palliative Medicine*, 17(7), 753-760. doi:10.1089/jpm.2013.0675
- Ghesquiere, A., Haidar, Y. M., & Shear, M. K. (2011). Risks for complicated grief in family caregivers. *Journal of Social Work End Life Palliative Care*, 7(2-3), 216-240. doi:10.1080/15524256.2011.593158
- Giovannetti, R., Reider, L., Wolff, J., Frick, K. D., Boulton, C., Steinwachs, D., & Boyd, C. (2013). Do older patients and their family caregivers agree about the quality of chronic illness care? *International Journal for Quality in Health Care*, 25(5), 515-524.
- Glaser, B. (1965). The constant comparative method of qualitative analysis. *Social Problems*, 12(4), 436-445.
- Glogowska, M., Simmonds, R., McLachlan, S., Cramer, H., Sanders, T., Johnson, R., . . . Purdy, S. (2016). "Sometimes we can't fix things": a qualitative study of health care

- professionals' perceptions of end of life care for patients with heart failure. *BMC Palliative Care*, 15(1), 3. doi:10.1186/s12904-016-0074-y
- Goldenheim, A., Oates, D., Parker, V., Russell, M., Winter, M., Silliman, R. (2014). Rehospitalization of older adults discharged to home hospice care. *Journal of Palliative Medicine*, 17(7), 2014. doi: 10.1089/jpm.2013.0224
- Goodlin, S. J. (2009). Palliative care in congestive heart failure. *Journal of the American College of Cardiology*, 54(5), 386-396. doi:10.1016/j.jacc.2009.02.078
- Hammond-Collins, K., Peacock, S., & Forbes, D., (2014). In sickness and in health: Comparing the experience of husbands and wives caring for someone with dementia. *Perspectives*, 37(3), 6-13.
- Harris, S., Adams, M., Zubatsky, M., & White, M. (2011). A caregiver perspective of how Alzheimer's disease and related disorders affect couple intimacy. *Aging & Mental Health*, 15(8), 950-960. doi: 10.1080/13607863.2011.583629
- Hankvisky, O., & Cormier, R. (2009). *Intersectionality: Moving women's health research and policy foward*. Retrieved from Vancouver, Canada: Women's Health Research Network.
- Hayes, S., Peloquin, S., Howlett, J., Harkness, K., Giannetti, N., Rancourt, C., & Ricard., N. (2015). A qualitative study of the current state of heart failure community care in Canada: What can we learn for the future? *BMC Health Services Research*, 15, 290. doi:10.1186/s12913-015-0955-4
- Heart and Stroke Foundation. (2011). *Billions of dollars at stake as Canada comes to grips with soaring heart failure costs*. Retrieved from <http://www.heartandstroke.sk.ca/>

- Heart and Stroke Foundation. (2015). *Heart failure*. Retrieved from http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3484065/k.9224/Heart_failure.htm
- Hollander, M., Liu, Guining, L., & Chappell, N. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 49. doi:10.12927/hcq.2009.20660 /a
- Hollway, W., & Jefferson, T. (2013). *Doing qualitative research differently* (2nd ed.). Los Angeles: SAGE.
- Hooley, P., Butler, G., & Howlett, J. (2005). The relationship of quality of life, depression, and caregiver burden in outpatients with Congestive Heart Failure. *Congestive Heart Failure*, 11(6), 303-310.
- Howlett, J., Morrin, L., Fortin, M., Heckman, G., Strachan, P. H., Suskin, N., . . . Arthur, H. M. (2010). End-of-life planning in heart failure: It should be the end of the beginning. *Canadian Journal of Cardiology*, 26(3), 135-141. doi:10.1016/s0828-282x(10)70351-2
- Howlett, J., Chan, M., Ezekowitz, J. A., Harkness, K., Heckman, G. A. M., Kouz, S., . . . Zieroth, S. (2016). The Canadian Cardiovascular Society Heart Failure Companion: Bridging Guidelines to Your Practice *Canadian Journal of Cardiology*, 32, 296-310. doi:<http://dx.doi.org/10.1016/j.cjca.2015.06.019>
- *Hupcey, J., Fenstermacher, J., Kitko, L., & Penrod, J. (2010). Achieving medical stability: Wives' experiences with heart failure. *Clinical Nursing Research*, 19(3), 211-229.

- *Hupcey, J., Fenstermacher, K., Kitko, L., & Fogg, J. (2011). Palliative needs of spousal caregivers of patients with heart failure followed up at specialized heart failure centers. *Journal of Hospice & Palliative Nurses*, 13(3), 142-150.
- Hupcey, J., Kitko, L., & Alonso, W. (2016). Patients' perceptions of illness severity in advanced heart failure. *Journal of Hospice & Palliative Nursing*, 18(2), 110-114.
doi:10.1097/NJH.0000000000000229
- Ivany, E. (2015). Understanding palliative care needs in heart failure. *British Journal of Cardiac Nursing*, 10(7), 348-353.
- Jo, S., Brazil, K., Lohfeld, L. & Willison, K. (2007). Caregiving at the end of life: Perspectives from spousal caregivers and care recipients. *Palliative and Supportive Care*, 5, 11–17.
doi: 10.10170S1478951507070034
- Johnson, A. (2015). Role of district and community nurses in bereavement care: A qualitative study. *British Journal of Community Nursing*, 20(10), 494-501.
- *Kaasalainen, S., Strachan, P., Brazil, K., Marshall, D., Willison, K., Dolovich, L., . . . Demers, C. (2011). Managing palliative care for adults with advanced heart failure. *Canadian Journal of Nursing Research*, 43(3), 38-57.
- Kang, X., Li, Z., & Nolan, M. T. (2011). Informal caregivers' experiences of caring for patients with chronic heart failure: Systematic review and metasynthesis of qualitative studies. *Journal of Cardiovascular Nursing*, 26(5), 386-394.
doi:10.1097/JCN.0b013e3182076a69
- *Kitko, L. A., & Hupcey, J. E. (2013). The work of spousal caregiving of older adults with end-stage heart failure. *Journal of Gerontological Nursing*, 39(7), 40-47.

- Kitko, L. A., Hupcey, J. E., Pinto, C., & Palese, M. (2015). Patient and caregiver incongruence in advanced heart failure. *Clinical Nurse Researcher*, 24(4), 388-400.
doi:10.1177/1054773814523777
- Kramer, B. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, 37(2), 218-232.
- Lee, J., Sohn, B. K., Lee, H., Seong, S., Park, S., & Lee, J. Y. (2016). Impact of behavioral symptoms in dementia patients on depression in daughter and daughter-in-law caregivers. *Journal of Womens Health*, 26(1), 36-43. doi:10.1089/jwh.2016.5831
- LeMond, L., & Allen, L. (2011). Palliative care and hospice in advanced heart Failure. *Progress in Cardiovascular Diseases*, 54(2), 168-178. doi:10.1016/j.pcad.2011.03.012
- Longo, C. J., Deber, R., Fitch, M., Williams, A. P., & D'Souza, D. (2007). An examination of cancer patients' monthly 'out-of-pocket' costs in Ontario, Canada. *European Journal of Cancer Care*, 16(6), 500-507. doi:10.1111/j.1365-2354.2007.00783.x
- Lu, Y., & Wykle, M. (2007). Relationships between caregiver stress and self-Care behaviors in response to symptoms. *Clinical Nursing Research*, 16(1), 29-43.
- Lum, H. D., Jones, J., Lahoff, D., Allen, L. A., Bekelman, D. B., Kutner, J. S., & Matlock, D. D. (2015). Unique challenges of hospice for patients with heart failure: A qualitative study of hospice clinicians. *American Heart Journal*, 170(3), 524-530.
doi:10.1016/j.ahj.2015.06.019
- *Luttik, M., Jaarsma, T., Veeger, N., van Veldhuisen, D. (2005). For better and for worse: Quality of life impaired in HF patients as well as their partners. *European Journal of Cardiovascular Nursing*, 4(1), 11-14. doi 10.1016/j.ejcnurse.2004.12.002

- Lynn, J. (2001). Serving patients who may die soon and their families: The role of hospice and other services. *Journal of the American Medical Association*, 285(7), 925-932.
- *MacKenzie, M., Buck, H., Meghani, S., & Riegel, B. (2016). Unique correlates of heart failure and cancer caregiver satisfaction with hospice care. *Journal of Pain and Symptom Management*, 51(1), 71-78. doi:<http://dx.doi.org/10.1016/j.jpainsymman.2015.09.001>
- Margetts, J., Le Couteur, A., & Croom, S. (2006). Families in a state of flux: the experience of grandparents in autism spectrum disorder. *Child: Care, Health and Development*, 32(5), 565-574.
- *Mårtensson, J., Dracup, K., & Fridlund, B. (2001). Decisive situations influencing spouses' support of patients with heart failure: A critical incident technique analysis. *Heart & Lung*, 30(5), 341-350.
- McBride, S. E., Beer, J. M., Mitzner, T. L., & Rogers, W. A. (2011). Challenges for home health care providers: A needs assessment. *Physical & Occupational Therapy In Geriatrics*, 29(1), 5-22. doi:10.3109/02703181.2011.552170
- McCarthy, P., Smedira, N., Vargo, R., Goormastic, M., Hobbs, R., Starling, R., & Young, J. (1998). One hundred patients with the Heartmate Left Ventricular Assist Device: Evolving concepts and technology. *The Journal of Thoracic and Cardiovascular Surgery*, 115(4), 904-912.
- McGuire, D., Grant, M., & Park, J. (2012). Palliative care and end of life: The caregiver. *Nursing Outlook*, 60(6), 351-356.
- *McIlvennan, C., Jones, J., Allen, L., Swetz, K., Nowels, C., & Matlock, D. (2016). Bereaved caregiver perspectives on the end-of-life experience of patients with a left ventricular

- assist device. *Journal of the American Medical Association: Internal Medicine*, 176, 534-538.
- *McMillan, S., Small, B., Haley, W., Zambroski, C., & Buck, H. (2013). The COPE intervention for caregivers of patients with heart failure: An adapted intervention. *Journal of Hospice & Palliative Nursing*, 15(4), 196-206.
- McWilliam, C. L., Ward-Griffin, C., Oudshoorn, A., & Krestick, E. (2008). Living while dying/dying while living: Older clients' sociocultural experience of home-based palliative care. *Journal of Hospice and Palliative Nursing*, 10(6), 338-349.
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G. T. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, 6(6). doi:10.1371/journal.pmed1000097
- Molloy, G. J., Johnston, D. W., & Witham, M. D. (2005). Family caregiving and congestive heart failure: Review and analysis. *The European Journal of Heart Failure*, 7(4), 592-603.
- Morgan, T., Ann Williams, L., Trussardi, G., & Gott, M. (2016). Gender and family caregiving at the end-of-life in the context of old age: A systematic review. *Palliative Medicine*, 30(7), 616-624. doi:10.1177/0269216315625857
- *Murray, S., Kendall, M., Boyd, K., Worth, A., & Benton, F. (2004). Exploring the spiritual needs of people dying of lung cancer or heart failure: a prospective qualitative interview study of patients and their carers. *Palliative Medicine*, 18(39), 39-45.
- National Collaborating Center for Methods and Tools. (2008). *Quality assessment tool for quantitative studies*. Retrieved from <http://www.nccmt.ca/resources/search/14>
- NVivo qualitative data analysis (Version 11) [Computer software]. QSR International.

- Park, M. (2012). Filial piety and parental responsibility: an interpretive phenomenological study of family caregiving for a person with mental illness among Korean immigrants. *BMC Nursing, 11*(28), 1-8.
- Parliament of Canada. (2000). *Quality end-of-life care: The right of every Canadian*. Retrieved from <http://www.parl.gc.ca/Content/SEN/Committee/362/upda/rep/repfinjun00-e.htm>
- Peacock, Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., . . . Henderson, S. R. (2010). The positive aspects of the journey with dementia: Using a strengths-based perspective to reveal opportunities. *Journal of Applied Gerontology, 29*(5), 640-659.
- Peacock, S. C. (2003). *A systematic review of interventions for unpaid caregivers of persons with dementia*. (Masters of Nursing), University of Saskatchewan, Saskatchewan.
- Penning, M. J., & Wu, Z. (2016). Caregiver stress and mental health: Impact of caregiving relationship and gender. *Gerontologist, 56*(6), 1102-1113. doi:10.1093/geront/gnv038
- Phillips, A. C., Gallagher, S., Hunt, K., Der, G., & Carroll, D. (2009). Symptoms of depression in non-routine caregivers: the role of caregiver strain and burden. *British Journal of Clinical Psychology, 48*(Pt 4), 335-346. doi:10.1348/014466508X397142
- Pinch, W. (1995). Synthesis: Implementing a complex process. *Nurse Educator, 20*(1), 34-40.
- Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *The Journal of Gerontology: Psychological Sciences, 61B*(1), P33-P45.
- *Pressler, S. J., Gradus-Pizlo, I., Chubinski, S. D., Smith, G., Wheeler, S., Sloan, R., & Jung, M. (2013). Family caregivers of patients with heart failure: a longitudinal study. *Journal of Cardiovascular Nursing, 28*(5), 417-428. doi:10.1097/JCN.0b013e3182563877

- Public Health Agency of Canada. (2013). *Preventing chronic disease strategic plan 2013-2016: Canadian living healthier and more productive lives*. Retrieved from http://publications.gc.ca/site/archivee-archived.html?url=http://publications.gc.ca/collections/collection_2014/aspc-phac/HP35-39-2013-eng.pdf
- Reimche, R., & Salcedo, D. (2016). Canadian palliative community Milirinone infusions: A case series. *Canadian Journal of Cardiovascular Nursing*, 26(1), 9-13.
- Saunders, M. (2008). Factors associated with caregiver burden in heart failure family caregivers. *Western Journal of Nursing Research*, 30(8), 943-959.
- *Saunders, M. (2012). Perspectives from family caregivers receiving home nursing support. *Home Healthcare Nurse*, 30(2), 82-90.
- *Scott, L. (2000). Caregiving and care receiving among a technologically dependent heart failure population. *Advances in Nursing Science*, 23(2), 82-97.
- *Scott, L. (2001). Technological caregiving: A qualitative perspective. *Home Health Care Management & Practice*, 13(3), 227-235.
- *Selman, L., Harding, R., Beynon, T., Hodson, F., Coady, E., Hazeldine, C., . . . Higginson, I. J. (2007). Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't." *Heart*, 93, 963-967.
- Shah, S., Carey, I., Harris, T., DeWilde, S., Victor, C., & Cook, D. (2013). The effect of unexpected bereavement on mortality in older couples. *American Journal of Public Health*, 103(6), 1140-1145. doi:10.2105/AJPH.2012.301050)
- *Small, N., Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., & Gariballa, S. (2009). Dying, death and bereavement: A qualitative study of the views of carers of people with heart failure in the UK. *BMC Palliative Care*, 8(1), 6. doi:10.1186/1472-684X-8-6

- Stajduhar, K. (2011). Chronic illness, palliative care, and the problematic nature of dying. *Canadian Journal of Nursing Research*, 43(3), 7-15.
- Stroebe, M., Schut, H., & Stroebe, W. (2007). Health outcomes of bereavement. *Lancet*, 370(9603), 1960–1973.
- Talley, R., & Crews, J. (2007). Framing the public health of caregiving. *American Journal of Public Health*, 97(2), 224.
- Tan, T., & Schneider, M. (2009). Humor as a coping strategy for adult-child caregivers of individuals with alzheimer's disease. *Geriatric Nursing*, 30(6), 397-408.
- Thorne, S., Con, A., McGuinness, L., McPherson, G. & Harris, S. (2004) Health care communication issues in multiple sclerosis: An interpretive description. *Qualitative Health Research*, 14(1), 5-22.
- Timonet Andreu, E., Morales Asencio, J. M., Canca Sanchez, J. C., Sepulveda Sanchez, J., Mesa Rico, R., & Rivas Ruiz, F. (2015). Effects and consequences of caring for persons with heart failure: (ECCUPENIC study) a nested case-control study. *Journal of Advanced Nursing*, 71(12), 2987-2997. doi:10.1111/jan.12732
- Torraco, R. J. (2005). Writing integrative literature reviews: Guidelines and examples. *Human Resource Development Review*, 4(3), 356-367. doi:10.1177/1534484305278283
- Ume, E. P., & Evans, B. C. (2011). Chaos and uncertainty: The post-caregiving transition. *Geriatric Nursing*, 32(4), 288-293. doi:10.1016/j.gerinurse.2011.06.009
- *Walden, J., Dracup, K., Westlake, C., Hamilton, M., Erickson, V., & Fonarow, G. (2001). Educational needs of patients with advanced heart failure and their caregivers. *The Journal of Heart and Lung Transplantation*, 20(7), 766-769.

- Whittemore, R., Chao, A., Jang, M., Minges, K. E., & Park, C. (2014). Methods for knowledge synthesis: an overview. *Heart Lung, 43*(5), 453-461. doi:10.1016/j.hrtlng.2014.05.014
- Whittemore, R., & Knafl, K. (2005). The integrative review: updated methodology. *Journal of Advanced Nursing, 52*(5), 546–553.
- Wingham, J., Frost, J., Britten, N., Jolly, K., Greaves, C., Abraham, C., & Dalal, H. (2015). Needs of caregivers in heart failure management: A qualitative study. *Chronic Illness, 14*(4), 304-319. doi:10.1177/1742395315574765chi.sagepub.com
- Wright, L., & Leahey, M. (2005). *Nurses and families* (4th ed.). Philadelphia: FA Davis Company.
- Zwaanswijk, M., Peeters, J., van Beek, A., Meerveld, J. & Francke, A. (2013). Informal caregivers of people with Dementia: Problems, needs and support in the initial stage and in subsequent stages of Dementia. *Open Nursing Journal, 7*, 6-13.
doi: 10.2174/1874434601307010006

Appendix A

Reference ID:

Reviewer:

Date:

Instructions for Completion:

1. Answer the following questions, circling Y or N for each relevance criterion.
2. To be included in the study, the article must meet all 6 criteria.

Relevance Criteria

1. Is the article written in English? Y or N
2. Is the article written in 1995 or later? Y or N
3. Does the article include a family caregiver over the age of 18? Criteria 1 is met if “Y” is answered for at least one of the following:

Spouse	Y or N	Grandchild	Y or N
Sibling	Y or N	Neighbour/Friend	Y or N
Adult child	Y or N		
4. Is the client considered to be in the advanced stages of heart failure (HF). Criteria met if the client is referred in the article as one of the following:

End of life	Y or N	Stage D (see note 1)	Y or N
Palliative	Y or N	Grade 3 (see note 2)	Y or N
Advanced HF	Y or N	Grade 4 (see note 2)	Y or N
5. Is the article considered to be one of the following:

Qualitative Research	Y or N
Quantitative Research	Y or N
Mixed Methods	Y or N
6. The article differentiates between the results from the caregiver and the client? Y or N
7. In the case of mixed populations, the article reports the finding from advanced HF separately from other population groups? Y or N

Reviewer Decision: Does the article meet the requirements of all 7 criteria? Y or N

Discrepancies: Do discrepancies exist between reviewers? Y or N

If yes, what was the reason for the discrepancy?	Y or N
Oversight	Y or N
Differences in interpretation of criterion	Y or N
Differences in interpretation of study	Y or N

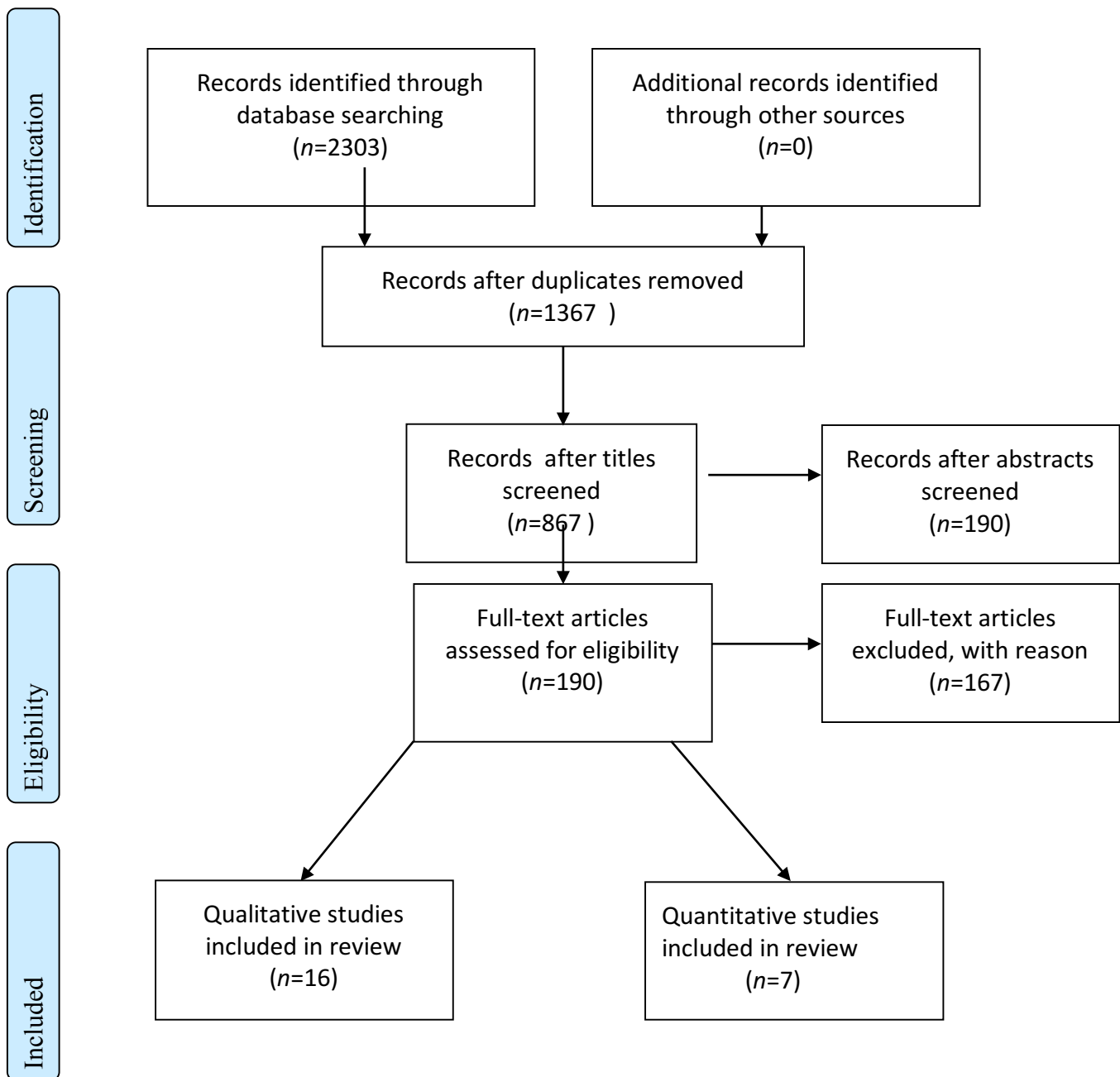
Final Decision: Will this study be included in the integrative review? Y or N

(adapted from Peacock & Forbes, 2003, p 76)

Note 1: Stage D as determined by the American College of Cardiology/American Heart Association **Note 2:** Grading according to the New York Heart Association (NYHA)

Appendix B

PRISMA 2009 Flow Diagram (Moher, Liberati, Tetzlaff, & Altman, 2009)



Appendix C

QUALITY ASSESSMENT TOOL FOR QUANTITATIVE STUDIES

COMPONENT RATINGS

A) SELECTION BIAS

Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60 – 79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted time series
- 7 Other specify _____
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C. No Yes

If Yes, was the method of randomization described? (See dictionary)

No Yes

If Yes, was the method appropriate? (See dictionary)

No Yes

RATE THIS SECTION STRONG MODERATE WEAK
See dictionary 1 2 3
RATE THIS SECTION STRONG MODERATE WEAK
See dictionary 1 2 3
Dictionary can be found at http://www.ehphp.ca/PDF/QADictionary_dec2009.pdf

C) CONFOUNDERS

(Q1) Were there important differences between groups prior to the intervention?

- 1 Yes
- 2 No
- 3 Can't tell

The following are examples of confounders:

- 1 Race
- 2 Sex
- 3 Marital status/family
- 4 Age
- 5 SES (income or class)
- 6 Education
- 7 Health status
- 8 Pre-intervention score on outcome measure

(Q2) If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?

- 1 80 – 100% (most)
- 2 60 – 79% (some)
- 3 Less than 60% (few or none)
- 4 Can't Tell

D) BLINDING

(Q1) Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Were the study participants aware of the research question?

- 1 Yes
- 2 No
- 3 Can't tell

E) DATA COLLECTION METHODS

(Q1) Were data collection tools shown to be valid?

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) Were data collection tools shown to be reliable?

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION STRONG MODERATE WEAK
See dictionary 1 2 3
RATE THIS SECTION STRONG MODERATE WEAK
See dictionary 1 2 3
RATE THIS SECTION STRONG MODERATE WEAK
See dictionary 1 2 3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Were withdrawals and drop-outs reported in terms of numbers and/or reasons per group?

- 1 Yes
- 2 No
- 3 Can't tell
- 4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

- 1 80 -100%
- 2 60-79%
- 3 less than 60%
- 4 Can't tell
- 5 Not Applicable (i.e. Retrospective case-control)

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

- 1 80 -100%
- 2 60-79%
- 3 less than 60%
- 4 Can't tell

(Q2) Was the consistency of the intervention measured?

- Yes
No
Can't tell

(Q3) Is it likely influence that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary 1 2 3 Not Applicable			

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution/individual/practice/office

(Q2) Indicate the unit of analysis (circle one)

community organization/institution/individual/practice/office

(Q3) Are the statistical methods appropriate for the study design?

- 1 Yes
- 2 No
- 3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

- 1 Yes
- 2 No
- 3 Can't tell

GLOBAL RATING COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A SELECTION BIAS STRONG MODERATE WEAK
123
B STUDY DESIGN STRONG MODERATE WEAK
123
C CONFOUNDERS STRONG MODERATE WEAK
123
D BLINDING STRONG MODERATE WEAK
123
E DATA COLLECTION METHOD
STRONG MODERATE WEAK
123
F WITHDRAWALS AND DROPOUTS
STRONG MODERATE WEAK
1 2 3 Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

- 1 STRONG
- 2 MODERATE
- 3 WEAK

With both reviewers discussing the ratings:

(no WEAK ratings)

(one WEAK rating)

(two or more WEAK ratings) Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings? No
Yes

If yes, indicate the reason for the discrepancy

- 1 Oversight
- 2 Differences in interpretation of criteria
- 3 Differences in interpretation of study

Final decision of both reviewers (circle one): 1 STRONG

2 MODERATE

3 WEAK

(National Collaborating Center for Methods and Tools, 2008)

Appendix D



Screening Questions

1. Was there a clear statement of the aims of the research?

- What was the goal of the research?
- Why it was thought important?
- Its relevance

☐ Yes ☐ Can't tell ☐ No

2. Is a qualitative methodology appropriate?

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

☐ Yes ☐ Can't tell ☐ No

Is it worth continuing?

Detailed questions

3. Was the research design appropriate to address the aims of the research?

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?


☐ Yes ☐ Can't tell ☐ No

4. Was the recruitment strategy appropriate to the aims of the research?

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

☐ Yes ☐ Can't tell ☐ No

5. Was the data collected in a way that addressed the research issue?

-  If the setting for data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
- If methods were modified during the study. If so, has the researcher explained how and why?
- If the form of data is clear (e.g. tape recordings, video material, notes etc)
- If the researcher has discussed saturation of data


☐ Yes ☐ Can't tell ☐ No

6. Has the relationship between researcher and participants been adequately considered?

- If the researcher critically examined their own role, potential bias and influence during
 - (a) Formulation of the research questions
 - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

☐ Yes ☐ Can't tell ☐ No

7. Have ethical issues been taken into consideration? ☐ Yes ☐ Can't tell ☐ No

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
-  If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

☐ Yes ☐ Can't tell ☐ No

9. Is there a clear statement of findings?

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researchers arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

☐ Yes ☐ Can't tell ☐ No

10. How valuable is the research?

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix E

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#1 Walden, Dracup, Westlake, Erickson, Hamilton and Fonarow (2001)</p> <p>Educational needs of patients with advanced heart failure and their caregivers.</p> <p><i>The Journal of Heart and Lung Transplantation.</i></p>	<p>To identify educational needs of patients with advanced HF and their caregivers.</p>	<p>Caregivers (n=72) of persons 18 years or older diagnosed with advanced HF (NYHA Class III-IV) and their caregivers (n=72).</p> <p>Mean age 52 55 female 17 male Relationship to patient not reported.</p> <p>HF patients (n=82) also completed questionnaire separately from the caregiver.</p>	<p>Quantitative</p> <p>One Questionnaire</p>	<p>Instrument developed by researchers to assess the educational needs.</p> <p>Likert scale</p>	<p>Top three identified caregiver needs- 1) desire for quality of life 2) honest explanations from professional members 3) information about how to react in an emergency situation</p> <p>Least important caregiver needs-1) patient appearance after transplant surgery 2)employment 3) information regarding sexual activity 4) time on own</p>	<p>Identified areas of need could be addressed first when teaching caregivers of persons with advanced HF.</p>	<p>United States</p> <p>76% of caregivers were female</p> <p>Rating: WEAK</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#2 Scott (2000)</p> <p>Caregiving and care receiving among a technologically dependent heart failure population.</p> <p><i>Advances in Nursing Science</i></p>	To determine measures of quality of life for patients with end-stage HF and their caregivers	<p>Caregivers (n=18) of patients with end stage HF receiving inotropic infusions in the community setting.</p> <p>Age range- 40-80 Mean age 63 16 female 2 male</p> <p>16 spouses 1 daughter 1 sister</p> <p>39% employed outside of the home</p> <p>Patients (n=20) also completed instruments separately from the caregiver.</p>	Quantitative Questionnaire	<p>The eight-item Caregiver Preparedness Scale</p> <p>The Minnesota Living with Heart Failure Questionnaire</p> <p>The 24-item Caregiver Reaction Assessment</p> <p>Mental Health Inventory-5 (MHI-5)</p> <p>The Quality of Life Index (QLI)</p>	<p>Caregivers felt somewhat prepared to handle their role.</p> <p>-most prepared to access and utilize resources and provide hands on care to patient - least prepared to manage emergency situations, manage stress and other psycho-social issues such as anxiety. Mental health scores of caregivers were below average</p> <p>-50% reporting anxiety -45% reporting depression and 39% reporting a loss of hope. Other concerns included finances, personal health, lack of time for own interests</p>	This information could be used to determine the caregiver's readiness to provide care to a person with advanced HF at home and how providing care in the home impacts on the caregiver's health and quality of life.	<p>United States</p> <p>89% of caregivers were females. 16 spouses, one sister and one daughter</p> <p>Rating: WEAK</p> <p>*Same data used as in article #20</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#3 Saunders (2012)</p> <p>Perspectives from family caregivers receiving home nursing support.</p> <p><i>Home Healthcare Nurse</i></p>	<p>Exploratory study that discusses the experience of caregivers of persons with HF who receive support through a home care agency.</p>	<p>Caregivers (n=11) of persons diagnosed with stage III or IV HF who had been hospitalized at least once in the past year</p> <p>Mean age 66</p> <p>4 male 7 female</p> <p>8 spouse 3 adult children</p> <p>10 white 1 Asian</p> <p>Caregivers interviewed in isolation from patient.</p>	<p>Qualitative Emergent design</p>	<p>Interview guide developed by the researcher</p> <p>Field notes Reflective notes</p>	<p>Supportive family, religious practices and home care support are seen as beneficial</p> <p>Mental and physical health is compromised</p> <p>Large amount of time spent on assisting with activities of daily living (ie dressing, eating)</p> <p>Hospitalizations were seen as challenging and were avoided</p> <p>-desire for personal time and for patient to regain health</p>	<p>Home care nurses Can play a key role improving the caregiving experience</p> <p>To support the caregiver the nurse can encourage self-care, facilitate communication within families and the healthcare team, provide education, advocate for enhanced home support services</p>	<p>United States</p> <p>Rating: STRONG</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#4 Pressler, Gradus-Pizlo, Chubinski, Smith, Wheeler, Sloan & Jung (2013)</p> <p>Family caregivers of patients with heart failure: A longitudinal study.</p> <p><i>Journal of Cardiovascular Nursing</i></p>	<p>To evaluate the differences between caregiving for persons with advanced HF and persons with a lower severity of symptoms.</p>	<p>Convenience sample of caregivers of persons with HF recruited from a HF clinic.</p> <p>Caregivers of persons with NYHA Class I and II (n=20)</p> <p>NYHA Class III and IV (n=43)</p> <p>Mean age 69</p> <p>15 male 48 female</p> <p>10 African American 53 Caucasian</p>	<p>Quantitative</p> <p>Interview at base-line, 4 months and 8 months</p>	<p>The Oberst Caregiving Burden Scale</p> <p>Control Attitudes Scale</p> <p>The Patient Health Questionnaire-8</p> <p>Brief Symptom Inventory Anxiety Subscale</p> <p>The Bakas Caregiving Outcomes Scale</p> <p>The Medical Outcomes Study Short-Form</p> <p>The Charlson Comorbidity Index</p>	<p>Caregivers of stage III and IV reported increased time spent on caregiving, higher anxiety, increased difficulty in caregiving tasks and lower physical health/quality of life compared to caregivers of persons with HF NYHA class I and II.</p>	<p>Caregivers of persons with advanced HF have increased needs and require additional supports to fulfill these needs.</p>	<p>United States</p> <p>Rating: WEAK</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
				The Family Functioning Assessment Device			
<p># 5 Murray, Kendall, Boyd, Worth & Benton (2004)</p> <p>Exploring the spiritual needs of people dying of cancer or heart failure: a prospective qualitative study of patients and their caregivers.</p> <p><i>Palliative Medicine</i></p>	To identify the spiritual needs of patients who are dying from HF or cancer and the needs of their caregivers.	<p>Purposive sample of caregivers (N=20) of persons dying from HF diagnosed with NYHA Class IV -Gender/age/ethnicity not reported.</p> <p>Caregivers (N=20) of persons dying from Cancer. Results reported separately from HF.</p> <p>Patients of persons with cancer or HF</p>	Qualitative interviews.	Interview guide developed by researchers.	<p>Caregivers have spiritual needs that are not being addressed.</p> <p>Potential for spiritual concerns included role conflicts, loneliness, isolation, reliance on others, negative perceptions of situation</p>	To allow health care professionals to identify spiritual needs so that they can be addressed	<p>United Kingdom</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
		also interviewed (n=40) Patients and caregivers could choose if they wanted to be interviewed together. Demographic data not reported.					
# 6 Mårtensson, Dracup and Fridlund (2001) Decisive situations influencing spouses' support of patient with heart failure: A critical incident technique analysis. <i>Heart & Lung</i>	To identify critical incidents that have a positive or negative effect on support that the pt receives from the informal caregiver.	Purposive sample of spouses (n=23) of patients with NYHA class III and IV HF. Age 62-86 Mean age 75 15 female 8 male All were spouses (n=23)	Qualitative descriptive design- Critical incident technique Semi-structured interviews for data collection		193 decisive situations identified that were categorized into two main themes 1) Involvement with others 2) Feeling like an outsider	The interactions that caregivers have with healthcare professionals have a direct impact on the caregivers ability to provide support to the pt.	Sweden Rating: MODERATE

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p># 7 Luttik, Jaarsma, Veeger & van Veldhuisen (2005)</p> <p>For better and for worse: Quality of life impaired in HF patients as well as their partners</p> <p><i>European Journal of Cardiovascular Nursing</i></p>	To assess the quality of life of patients with NYHA Class III and IV HF and their partners.	<p>Caregivers (n=38) of persons with advanced HF</p> <p>Mean age 68</p> <p>32 female 6 male All spouses</p> <p>Patients (n=39) also included in the study. Caregivers and patient were questioned separately.</p>	Prospective, retrospective and present one time quantitative-questionnaire	<p>Cantril Ladder of Life (to assess quality of life)</p> <p>Previously used in studies looking at cardiac diagnoses.</p> <p>Validity reported, not reliability.</p>	<p>Informal caregivers of persons with HF had lower quality of life (QOL) measures than the general population but better than patient except at times of hospitalization where QOL measures were lower for caregivers. Little variation in caregiver reported measures between past present and future.</p>	Caregivers have needs that could be addressed to improve quality of life.	<p>Netherlands</p> <p>Rating: WEAK</p>
<p>#8 Kitko & Hupcey (2013)</p> <p>The work of spousal caregiving of older adults with end-stage heart failure.</p> <p><i>Journal of Gerontological Nursing</i></p>	To gain an understanding of the work the caregiver of a patient with end-stage HF.	<p>Spousal caregivers (n=20) of a person with stage D HF or NYHA class 3 or 4</p> <p>Mean age 67 Age range 46-78</p> <p>14 women 6 men</p>	Qualitative	In person and telephone interviews.	<p>Work of the spousal caregiver included providing care (physical and emotional care), navigating the system (medical, financial, government), maintaining self, managing the household (income,</p>	Article indicates that caregivers need assistance with their “work” as a caregiver. This article identifies areas where education/support may be needed.	<p>United States.</p> <p>Sole focus of article is on caregivers.</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
		90 Caucasian 10 African American Range of caregiving from 2 months to 9 years.			compensating for pts previous roles) Vigilance (constantly monitoring pt), Normalcy (organizing daily events around fluctuating health status, developing routines)		
#9 Kaasalainen, Strachan, Brazil, Marshall, Willison, Dolovich, Taniguchi & Demers (2011) Managing palliative care for adults with advanced heart failure. <i>Canadian Journal of Nursing Research</i>	An exploration of community services provided to persons dying from HF and barriers that they experience from the perspectives of the patient, caregiver and health care professionals.	Family caregivers of persons with NYHA class IV (n=10) Mean age 65 Age range 35-85 7 spouses 3 adult children 8 female 10 male Patients (n= 8) and health care professionals (n=17) also interviewed for this study but	Qualitative.	Semi-structured interviews.	Challenges- manage role, accessing resources, transitioning from cardiac care team to palliative team, caring for own physical/mental health, increased role responsibility, isolation Effective care- Inter-professional teams Coping strategies- spiritual, importance of marriage	Results indicate palliative needs for patients/caregivers of persons dying from HF and could be used to inform future program development.	Canada Rating: STRONG

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
		caregivers were interviewed separately.					
<p>#10 Hupcey, Fernstermacher, Kitko and Penrod (2010)</p> <p>Achieving medical stability: Wives' experiences with heart failure.</p> <p><i>Clinical Nursing Research</i></p>	<p>To identify palliative care needs of wives caring for persons with advanced HF. To present case studies from the perspective of multiple illness trajectories as experienced by wives caring for persons with palliative HF less than 65 years of age.</p>	<p>26 caregivers were interviewed in the original study, 5 case studies were drawn from this data</p> <p>Mean age 55.7 Age range 27-68</p> <p>All spouses All female</p>	<p>Qualitative case studies. derived from multiple interviews</p>	<p>None identified.</p>	<p>Case 1:Sudden death- unexpected shock, reflection needed to process death</p> <p>Case 2: Slow decline-gradual increase of responsibilities, feeling loss of previous abilities, increase in financial difficulties</p> <p>Case 3: Awaiting heart transplant- Fear of the unknown, financial burden, coming to terms</p>	<p>The needs of caregiver fluctuate as the health status of the pt changes. Health care professionals have a role to play in addressing these needs and can use these case studies as a basis to prepare the caregiver for potential future experiences and needs.</p>	<p>United States</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					<p>Case 4: After device placement- anxiety related to device function, enhanced function with lack of clarity on how long these improvements would last, living in the moment</p> <p>Case 5: Slow decline with hospice- sense of peace, period of mourning</p>		

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#11 Dracup et al. (2004)</p> <p>Emotional well-being in spouses of patients with advanced heart failure.</p> <p><i>Heart and Lung</i></p>	<p>To measure the sense of well-being of spouses of persons with advanced HF and identify potential factors the influence well-being including how feelings of control influence reported measurements.</p>	<p>Non-probability sample of spouses (n=69) of patients with advanced HF.</p> <p>Spouses were primary caregivers and lived in the same household.</p> <p>52 female 17 male</p> <p>Mean age 54 Age range 30-77</p> <p>62% were employed outside the home</p>	<p>Cross-sectional correlational design</p>	<p>Emotional wellbeing measurement using the 36 item short form health survey (SF-36)</p> <p>Perceived control measure using the Control Attitudes Scale-Family Version</p> <p>Caregiver burden-Caregiver Appraisal Tool</p>	<p>Well-being measures were lower than for the average population.</p> <p>Age appeared to influence sense of well-being with younger ages reporting lower levels.</p> <p>Feelings of control had a positive influence on well-being whereas perceived caregiver burden had a negative influence on well-being</p>	<p>Spouses of persons have increased needs that should be identified by the health care practitioner with special attention to be paid to younger spouses.</p> <p>Interventions that influence perceived control could potentially improve well-being.</p>	<p>United states</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#12 Davidson, Abernethy, Newton, Clark & Currow (2013)</p> <p>The caregiving perspective in heart failure: A population based study.</p> <p><i>BMC Health Services Research</i></p>	To identify unique characteristics of caregivers of persons diagnosed with palliative HF.	<p>Caregivers of persons with HF who had died in the past 5 years (n=84)</p> <p>Caregivers of persons with other life limiting illnesses who had died in the past 5 years (n=1420)</p> <p>Average age 55.7</p> <p>Female n=54 Male n=30</p> <p>16.7% of respondents reported they were a spouse of the person who had died from HF.</p>	Quantitative population based study	Data extracted from the South Australian Health Omnibus which is a random survey that is administered in person with telephone follow-up.	<p>HF caregivers with older, less likely to consult with palliative care services prior to death and less likely to received assistance with hands on care.</p>	<p>Need for address barriers to accessing palliative services for families affected by advanced HF.</p> <p>Health practitioners could intervene by arranging for assistance with physical care or providing education to enhance ability for caregiver to manage complex tasks on own.</p> <p>Identifies need for prospective studies.</p>	<p>Australia</p> <p>Rating: STRONG</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#13 Brush, Budge, Alharethi, McCormick, MacPherson, Reid, Ledford, Smith, Stoker, Clayson, Doty, Caine, Drakos & Kfoury (2010)</p> <p>End of life decision making and implementation in recipients of destination left ventricular assist devices.</p> <p><i>The Journal of Heart and Lung Transplantation</i></p>	<p>To identify issues that caregivers and patients encounter during the end of life period when a patient has a left ventricular assist device.</p>	<p>Bereaved caregivers (n=20) of patients with HF who had actively made end of life decisions.</p> <p>17 spouses and 2 adult children</p> <p>Age and gender not reported.</p>	<p>Qualitative interviews</p>	<p>None identified.</p>	<p>Caregivers participated in end of life discussions regarding discontinuation of the LVAD and at times, initiated the conversation. This discussion occurred with the health care team. Multiple caregivers in the study felt comforted by this conversation. Educational needs included information of experience of dying once pump was turned off and how to manage side effects of pump removal such as anxiety, pain and shortness of breath.</p>	<p>Health professionals need to be informed of needs of patients with LVAD's so that they can be comfortable talking about considerations for end-of-life when the LVAD pump nears the end of its lifespan or potential for discontinuation of pump is initiated by the caregiver.</p>	<p>United States</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#14 Brannstrom, Ekman, Boman & Strandberg (2007).</p> <p>Being a close relative of a person with severe, chronic heart failure in palliative advanced home care: A comfort but also a strain.</p> <p><i>Scandinavian Journal of Caring Science</i></p>	<p>To gain an understanding of the lived experience of being a relative of a person with advanced HF (NYHA class III and IV) who receives palliative home care.</p>	<p>Caregivers of a person with palliative HF (n=3)</p> <p>2 spouses 1 daughter</p> <p>3 female</p> <p>Age range 50-75</p>	<p>Qualitative-phenomenological-hermeneutic interpretation</p>	<p>Open ended question interview guide</p>	<p>Palliative home care reduces feelings of burden for the close relative, reduced need for medical/hospital visits, improves quality of life by reducing isolation, improves relative's health status, despite support from palliative home care, caregivers experienced emotional and physical burden. Relatives expressed a need to maintain normality (i.e. visiting friends, getting out for a walk)</p>	<p>Palliative home care is valuable for caregivers of persons with advanced HF therefore referrals should be sought however relatives continue to have needs that are not being addressed by the team. Interventions to meet these needs should be developed.</p>	<p>Sweden</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#15 Aldred, Gott & Gariballa (2003)</p> <p>Advanced heart failure: impact on older patients and informal carers</p> <p><i>Journal of Advanced Nursing</i></p>	To describe the impact of advanced HF on the patient and the caregiver.	<p>Partners (n=10) of patients with advanced HF.</p> <p>4 men 6 women</p> <p>Ages not reported.</p> <p>Results from patients with advanced HF (n=10) also included in the study. Patients and caregivers were interviewed together.</p> <p>Includes one same sex couple.</p>	Qualitative	<p>Research guide that had been piloted.</p> <p>Open ended questions.</p>	<p>Negative impact included loss of social network/ feelings of isolation/reduced time with family.</p> <p>Lack of information about diagnosis, healthcare practitioners lacked time to provide support.</p> <p>Caregivers wanted information on the experience of dying but felt uncomfortable talking to patients about their death.</p> <p>Communication issues- unclear who to contact regarding concern.</p> <p>Desire to reduce time in hospital.</p> <p>Caregiver provided</p>	<p>Caregivers of person with advanced HF have needs that are not being addressed.</p> <p>Caregivers would like to have discussions about the experience of end of life with health care professionals.</p>	<p>United Kingdom</p> <p>Rating: STRONG</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					emotional/physical support		
<p>#16 Small et al. (2009)</p> <p>Dying, death and bereavement: a qualitative study of the views of carers of people with heart failure in the UK.</p> <p><i>BMC Palliative Care</i></p>	<p>To describe the end of life and bereavement period for caregivers of persons who died from HF.</p>	<p>Bereaved caregivers (n=20)</p> <p>13 spouses 6 daughters 1 son</p> <p>17 female 3 male</p> <p>Age- 7 under 60 5 between 60-70 8 over 70</p>	<p>Qualitative interviews</p>	<p>Interview guide.</p>	<p>Lack of discussion about the end of life experience prior to death.</p> <p>Caregivers found support from spiritual beliefs.</p> <p>Sudden death at home preferred over slow decline or death in hospital however this was not the case in all situations.</p> <p>Caregivers recalled unnecessary tests prior to death and this reduced</p>	<p>Caregivers need assistance in how to approach the topic of death with the patient.</p> <p>Although many caregivers prefer death to occur at home, this isn't always the case and important that health care professionals discuss end of life plan.</p> <p>Health care professionals to analyze whether an ordered test is required if patient considered nearing end of life</p>	<p>United Kingdom</p> <p>17 out of 20 were female</p> <p>Rating: STRONG</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					<p>feelings of peace at end of life.</p> <p>Depression and isolation were common in the bereavement period.</p> <p>Strategies to deal with bereavement period- join activities, socialize, take time to grieve</p> <p>Lack of support from professionals after death.</p> <p>Caregivers concerned with burdening family members with discussions on grief.</p>	<p>and have discussion with caregiver to give them an opportunity to decline tests.</p> <p>Important to set up follow-up for caregivers of persons with HF who have died.</p>	

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#17 Buck, Zambroski, Garrison & McMillan (2013)</p> <p>Everything they were discussing, we were already doing. Hospice heart failure caregivers reflect on a palliative caregiving intervention.</p> <p><i>Journal of Hospice and Palliative Nursing</i></p>	<p>To determine if the COPE (creativity, optimism, planning, and expert information) intervention is effective for caregivers of persons with advanced HF</p>	<p>Caregivers (n=7) of persons with HF who utilized hospice services in the Southern US.</p> <p>Age range 78-94</p> <p>4 spouses 1 daughter 1 son 1 brother</p> <p>5 female 2 male</p>	<p>Qualitative interviews</p>		<p>Intervention not useful for experienced caregivers.</p> <p>Caregivers reporting positive experience with hospice care were less likely to utilize expert information on symptom management.</p> <p>Symptom management check lists not useful.</p> <p>In some cases, the intervention served to increase caregiver burden.</p> <p>The information presented during the intervention confirmed to multiple caregivers that they were doing a good job in their role.</p>	<p>Caregivers need interventions earlier in the disease process.</p> <p>Quality of care at end of life influences the experience of the caregiver.</p>	<p>United States</p> <p>COPE Intervention</p> <p>Caregivers recruited from pilot study to further investigate reasons why COPE intervention was ineffective.</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					One caregiver was able to recognize symptoms of depression and seek support due to the intervention.		
<p>#18 Selman Harding, Beynon, Hodson, Coady, Hazeldine, Walton, Gibbs, & Higginson (2006)</p> <p>Improving end-of-life care for patients with chronic heart failure: "Let's hope it'll get better, when I know in my heart of hearts it won't"</p> <p><i>Heart: British Medical Journal</i></p>	To develop guidelines for end of life care for persons with advanced HF	<p>Informal caregivers (n=11) of persons with advanced HF</p> <p>No further data reported for caregivers.</p> <p>Results also obtained from patients with advanced HF (n=20) and professional caregivers (n=12)</p> <p>Patients/ caregivers/ professionals were</p>	Qualitative semi structured interviews		<p>Some caregivers felt if the it would be ok to discontinue active treatment if the pt was having uncontrolled pain, low quality of life or decline mental function whereas other caregivers felt that was the decision of the physician or the patient.</p> <p>Discussion between physician and caregiver around end of life was limited. Caregivers admit that at times they</p>	<p>Caregivers need to be involved in end of life discussions as this is a source of anxiety for them.</p> <p>Caregivers should be encouraged to talk about end of life preferences and to have these discussions with pts.</p>	<p>United Kingdom.</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
		interviewed separately.			avoided the conversation. Anxiety, dread and guilt were common themes for caregivers.		
<p>#19 Hupcey, Fenstermacher, Kitko & Fogg (2011)</p> <p>Palliative needs of spousal caregivers of patients with heart failure followed up at specialized heart failure centers.</p> <p><i>Journal of Hospice & Palliative Nursing</i></p>	To identify the changing needs of caregivers of persons with advanced heart as the disease progresses through the palliative period.	<p>Informal caregivers of persons with advanced HF (N=45) recruited from a heart failure clinic.</p> <p>39 female 6 male</p> <p>All spouses</p> <p>age 27- 76</p>	<p>Qualitative (grounded theory)</p> <p>Goal for 12 interviews for each participant. N=37 Completed all interviews.</p>	Interview guide- open ended questions.	<p>Needs changed based on the disease trajectory.</p> <p>Informational needs during illness instability- focused on present concerns i.e. advanced care directives and expected health outcomes of the pt, caregivers reported use of jargon was limiting understanding</p> <p>During stability, information needs included new treatments, future</p>	<p>Caregivers have needs that should be addressed by professionals both during periods of stability and instability.</p> <p>The health issues of caregivers need to also be addressed.</p> <p>We expect a lot from caregivers and it appears their needs are not being adequately addressed, especially during periods of pt stability.</p>	<p>United States.</p> <p>Rating: MODERATE</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					<p>planning, diet management</p> <p>Financial needs- during instability- medical bills, accommodations, inability to work due to needing to be at the hospital</p> <p>Stable- searching for money (i.e. applying for disability, support from family, bringing in extra income</p> <p>Psychosocial needs- unstable- desire for respite but not always possible, lack of support creates conflict within the family</p> <p>Stable-resentment towards pts inability or lack of desire to assist in household chores, marital conflict</p>	Information should be provided in common language to enhance understanding.	

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					<p>spiritual/emotional support, therapy or support group, high stress levels</p> <p>Physical needs</p> <p>Unstable- overwhelmed by physical care required to support pt i.e. medical changes and new devices- tired from multiple roles in addition to caregiving i.e. work/caring for children/adult parent</p> <p>Stable- caregivers were able to address their own health needs</p>		

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
#20 Scott (2001) Technological Caregiving: A Qualitative Perspective <i>Home Health Management and Practice</i>	To describe the experience of caregiving for a person with end-stage HF who are dependent on inotropic infusions.	Caregivers who provide care for a person with end-stage HF who assists with giving inotropic infusions in the home environment or ambulatory care (n=4) All spouses 3 female 1 male mean age 71.25	Qualitative-interviews	Interview guide	Positive (increased self-esteem, normalcy, additional time with spouse, fewer hospitalizations required) and challenging experiences reported specifically noted were financial, psychosocial (depression), self-care (lack of sleep, nutrition deficit or overeating), behavioral (changing role patterns) Fear of unknown future/lack of routine Feeling unprepared to fulfill role of “nurse” Feelings of obligation to provide care	Positive aspects of caregiving could be highlighted in discussions with caregivers who are feeling burdened. If caregivers are given support to take on additional caregiving roles in a community setting, it could reduce hospitalizations and improve normalcy within the family unit. Caregivers should be screened for identified challenges to allow for them to be addressed in a timely matter. Caregivers should be encouraged to maintain self-care.	United States Rating: MODERATE *Same data used as in article #2

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					Territorial of patient care provision Socially isolated Increased role responsibilities Anxiety about death of spouse		

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
#21 McMillan (2013) The COPE Intervention for Caregivers of Patients with Heart Failure <i>Journal of Hospice and Palliative Nursing</i>	To test the effectiveness of the COPE Intervention for caregivers of patients with HF.	Caregivers (n=40) of patients with end stage HF who provide at least 4 hours of care per day. Patient (n=40) data were also included in the results Mean age 63.3.6 Average 12 years' education 85% white female n=28 male n=12 65% married 17 spouses 16 adult children 7 relationship not reported 4 caregivers were working	Quantitative Two-group mixed-methods comparative experimental design with repeated measures (baseline, 4 weeks and 5 weeks). Creativity, Optimism, Planning, and Expert information (COPE) Intervention- A problem based intervention-educational manual given to caregiver that presented common patient problems and solutions. Caregivers received three visits and two follow-up phone calls where questions were answered and teaching was reinforced.	Caregiver Quality of Life Index- 35 items- 5-point scale Caregiver Anxiety and Depression- 9 items- 5-point rating scale Hospice Quality of Life Index- 28 item self-report tool Caregiver Demands Scale- stress of 46 caregiving tasks rated on 0-5 scale Perceived Illness-Related Stressors in Caregivers- stress of pt symptom	No significant differences between groups related to depression scores, caregiver distress, anxiety, quality of life or knowledge pre or post intervention.	COPE intervention could be useful in Early HF diagnosis. Other interventions need to be explored with caregivers who provide care for persons with HF in the advanced stages as they continue to have needs that are unaddressed.	United States Rating: STRONG

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
		Caregivers receiving intervention and normal care (n=19) Normal care (n=21)		rated on 0-5 scale Caregiver Knowledge Test- pre and post to assess knowledge related to caregiving tasks			

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#22</p> <p>MacKenzie A., Buck, H., Meghani, S. & Riegel, B., (2016).</p> <p>Unique correlates of heart failure and cancer caregiver satisfaction with hospice care</p> <p><i>Journal of Pain and Symptom Management</i></p>	<p>To determine correlates to caregiver satisfaction with hospice care for persons dying from heart failure in comparison to persons with cancer.</p>	<p>7324 caregivers of persons who died from heart failure</p> <p>-average age 65 -23,871</p> <p>Results compared to caregivers of persons who died from cancer</p> <p>-94% white</p> <p>5420 female 1904 male</p>	<p>Quantitative</p> <p>-retrospective cohort study of national hospice data</p>	<p>FEHC is a 61-item questionnaire-</p> <p>-distributed 1-3 months after patient's death</p> <p>-Likert scale</p>	<p>Care in nursing home was related to reduced caregiver satisfaction</p> <p>Higher caregiver education was correlated with higher overall caregiver satisfaction.</p> <p>Caregivers who perceived that the person with HF was experiencing high levels of dyspnea and pain were less likely to be satisfied with hospice care.</p> <p>93% reported satisfaction with symptom management in hospice</p> <p>70% satisfaction with emotional support in hospice</p>	<p>Due to 94% of the sample being white, satisfaction with the experience of hospice for different cultural groups remains unclear.</p> <p>Areas for improvement within hospice care include teaching needs, supports in nursing homes and symptom management (anxiety, dyspnea and pain). This study illustrates that focus in these areas could result in significant improvements to caregiver satisfaction with hospice.</p>	<p>United States</p> <p>Rating: WEAK</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					<p>59% satisfied with teaching in hospice</p> <p>Higher educational attainment was associated with lower satisfaction with emotional support and provided teaching in hospice.</p> <p>82% satisfied with care coordination.</p> <p>Older caregivers reported higher satisfaction with care coordination.</p> <p>Caregivers utilizing larger hospice facilities, persons caring for pts that reported high levels of anxiety and female caregivers were less satisfied with teaching.</p>		

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					Non spousal caregivers and younger caregivers reported higher satisfaction with teaching.		

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
<p>#23</p> <p>McIlvennan, C., Jones, J., Allen, L., Swetz, K., Nowels, C., & Matlock, D. (2016)</p> <p>Bereaved Caregiver Perspectives on the End-of-Life Experience of Patients with a Left Ventricular Assist Device</p> <p><i>Journal of the American Medical Association: Internal Medicine</i></p>	<p>To understand the experience of bereaved caregivers and patients at the end of life who have an LVAD.</p>	<p>Caregivers of persons who died from HF (n=8) 2 months to 2 years post death</p> <p>Median age- 64 Age range 54-71</p> <p>6 female 2 male</p> <p>5 spouses 2 friends 1 mother</p>	<p>Semi structured, in-depth interviews were conducted between September 10 and November 21, 2014, with 8 bereaved caregivers of patients with an LVAD who were recruited from a single institution. Data were analyzed from December 13, 2014, to February 18, 2015, using a mixed inductive and deductive approach.</p>		<p>Themes: (1) confusion about the process of death with an LVAD- concern with professionals lack of understanding of pump function, anxiety about how death would occur and surprise that pt was nearing end of life (2) confusion about the legal and ethically permissible care of patients approaching death with an LVAD- i.e. determining the appropriate time to turn off the pump and whether turning of the pump was considered suicide or murder (3) confusion about the fragmented integration of palliative and hospice care-</p>	<p>Discussions around end of life should be initiated when LVAD implanted to allow caregivers time to prepare emotionally.</p> <p>Ethics may need to be involved if a patient/caregiver would like to discontinue treatment with LVAD.</p> <p>Palliative team consulted earlier in the process to allow time for gradual transfer of care to palliative care team.</p> <p>Consider having a palliative care specialist on the cardiology team so that they are familiar to the caregiver.</p>	<p>United States.</p> <p>Rating: STRONG</p>

Source/Title	Purpose/Problem	Sample	Design	Instrument	Results related to caregivers	Implications	Country of Origin /Comments/ Quality Appraisal Score
					feelings of abandonment from cardiology team		